

# REAL-WORLD IMPLEMENTATION OF THE BIOPSYCHOSOCIAL APPROACH TO HEALTHCARE: PRAGMATIC APPROACHES, SUCCESS STORIES AND LESSONS LEARNED

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# Editorial: Real-world implementation of the biopsychosocial approach to healthcare: Pragmatic approaches, success stories and lessons learned

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## Editorial on the Research Topic

Real-world implementation of the biopsychosocial approach to healthcare: Pragmatic approaches, success stories and lessons learned

In 1977, George Engel's landmark paper (1) challenged the medical community to re-think how healthcare could be conceptualized, taught and practiced. Engel—an internist and psychoanalyst who spent much of his career in the Department of Psychiatry at the University of Rochester—pointed to the importance of widening our view from the still-important biomedical aspects of disease and illness to also examine psychological and social factors of influence. He was particularly concerned with the idea of reductionism (that illness can be attributed to one singular cause), and mind-body dualism (the notion that the mind and the body operate completely independently of one another). As a psychoanalyst, Engel was trained to focus on the role patients' beliefs, behaviors and relationships played in their experiences of health and disease. Perhaps this also allowed him to become more acutely aware of how clinicians' belief systems could limit conceptualization of disease. He wrote, "The historical fact we have to face is that in modern Western society, biomedicine not only has provided a basis for the scientific study of disease, it has also become our own culturally specific perspective about disease, that is, our folk model." He set out to encourage clinicians to embrace a more comprehensive understanding of the psychosocial aspects of health that can

influence how health is experienced as well as the course of disease and the trajectory of recovery. The timing of Engel's paper was ideal; there was a growing movement of concern that medical care was becoming increasingly specialized and de-humanized (2). The biopsychosocial (BPS) approach provided a helpful framework for the time.

Today, many in healthcare are once again reconceptualizing the pitfalls of the still predominant biomedical approach to healthcare. The COVID pandemic has reinforced systemic health inequities (3) and public mistrust of mainstream healthcare is on the rise (4). At the same time, surmounting evidence over the last several decades shows that psychosocial stressors in early childhood have physiological and immune modulating effects on the body (5, 6) and that structural determinants reinforce health inequities and exacerbate such stressors (7). Hence, the value of the BPS approach remains even more relevant today, perhaps with greater attention to the role of the nuances of the social component of the BPS. The BPS framework is also relevant in a health system that increasingly recognizes the importance of health care teams to expand the scope of expertise of those in healthcare to the psychological and social realms, as well as to address the dramatically increasing burden and burnout of physicians and nurses (8).

With this Research Topic, we sought to survey how the BPS approach is being conceptualized, adapted and improved in the current climate of healthcare challenges internationally. We invited authors to tell us how they are using the BPS pragmatically in clinical and community settings, and we encouraged them to tell us about the ways in which they are adding to the framework and working across disciplines to address each component. We found that clinicians and researchers across the world are actively thinking about and implementing components of the BPS framework, adapting the approach to address the challenges they face caring for an ever increasingly complex set of concerns, and continuing to define the BPS framework to incorporate important changes in the way healthcare is being delivered and experienced today. We have categorized the manuscripts in this special edition to highlight four main cross-cutting themes: 1. Conceptualization and additions to the BPS approach; 2. The use of the BPS to approach to address health-related issues with etiologies and treatments that reach beyond the historically defined (though often arbitrary) biomedical boundaries of medical care; 3. Description of the opportunities and challenges of interprofessional teamwork to actualize components of the BPS framework; and 4. Reports of educational innovations related to the BPS approach. Below we describe each theme and discuss key insights from the papers in this Research Topic.

## Conceptualization and additions to BPS approach

The BPS approach is reflective of the general systems model that permeated physics, biology, and eventually the social sciences in the mid-20th century. While lauded for its "clinical merit," the BPS approach has been criticized as "underdeveloped" as a scientific model due to its vagueness (9, 10). Nonetheless, the pragmatic tenets of attending to biological, psychological and social components of health are compelling, with many clinicians and researchers desiring to add specificity and theoretical rigor to how the BPS approach can be incorporated in practice (11), including the additions in this section. Several focus on the need to expand the BPS approach to address psychosocial components of health, such as the role of family and relational aspects of health. Wood et al. take up the challenge through their development of the Biobehavioral Family Model (BBFM), which identifies specific pathways by which family relationships impact disease activity through psychobiological mechanisms. Schwartz et al. review the literature and make a policy argument for systemic change in intensive care units to embrace "family centered care" so that "family members feel respected as valued members of the care team." In their perspective paper Hiefner and Villareal similarly recommend adding a family-oriented, multidisciplinary approach to caring for patients and families after a miscarriage. Podgorski et al. take a slightly different tack, invoking the Socioecological Model with regard to dementia caregiving to consider the impact and context of illness within family relationships and social networks.

Each of the above papers add specificity to the psychosocial aspects of the BPS approach or address explicit frameworks for BPS implementation. In doing so, they invite us to question just how many aspects of a holistic model should be incorporated at any one time: should emotional and family factors be considered in addition to or separate from other interpersonal factors? Should cultural factors be included in addition to historical systems, and in which context? Ventres and Frankel address this line of questioning head-on, stating "the BPS model is not set in stone, but an inspiration for further integrating BPS concepts into practice." Using the concepts of "add ons" and "add ins," they suggest that clinicians can take personal ownership over the BPS approach, flexing and focusing as relevant.

## Using the BPS to develop new solutions to complex health challenges

The BPS approach may be particularly helpful in developing solutions to health-related challenges that have been limited by

the arbitrary boundaries of healthcare settings where people often seek care. For example, [Hou et al.](#) use the BPS approach to consider the impact of migration and isolation on health needs of women affected by intimate partner violence in rural China. [Guo et al.](#) use the BPS approach to examine the relationship between adherence to traditional Chinese post-partum practices and post-partum depression and [Duberstein et al.](#) use the BPS approach to identify personal, psychological, social and family contexts that impact pre- and post-natal care utilization in the community. [Van Orden et al.](#) demonstrate ways in which the electronic health record can be leveraged to assess patient-reported outcomes (PROs) and thereby develop population-based strategies for addressing BPS needs in a health system. [Chen et al.](#) describe a layperson-delivered intervention using a BPS framework to address psychiatric support needs in low and middle-income countries suffering from lack of resources and specialized trained professionals. [Schaefer et al.](#) conducted a cross-country survey to assess the range of psychological and psychiatric consultation and liaison (CL) services that arose in the context of COVID. Using a BPS perspective, they consider their findings that CL services provide for healthcare workers and families in addition to patients and suggest ways of working with administration and across systems to bolster CL services. [Köbler et al.](#) use the BPS framework to discuss a new type of integrated medical- psychiatry unit targeted to patients with medical conditions (“somatically ill patients”) that otherwise limit their ability to receive focused treatment. [Stoll et al.](#) use the BPS framework in a study of psychiatrists’ attitudes toward Palliative Psychiatry- a new approach to care for patients with severe mental illness which includes assessment of existential factors of care. By comparing attitudes of psychiatrists in India to psychiatrists in Switzerland, the authors were able to ascertain one potential way to improve adoption of Palliative Psychiatry by taking a more inclusive stance on which treatments would fall under palliation. The authors in this section each build on the BPS approach as the rationale and scaffolding for development of healthcare interventions that live at the borders of traditional conceptualizations or accepted biomedical treatment.

## Teamwork and the BPS approach

The evolution of implementing a BPS approach led inevitably to teamwork. In practice, clinicians may become adept at assessing the biological, psychological and social components of health, yet patients with more complex BPS needs might benefit from collaboration of experts in the biological, psychological and social spheres of healthcare. [Xiao et al.](#) note that, despite wide-spread knowledge of the importance of the BPS approach, including in China, there is still little known about its practical implementation. Their mixed-methods study aimed to assess how the BPS approach is applied in a large tertiary hospital in China. They found

that despite an interest in the BPS approach, few clinicians are incorporating the three essential components of the BPS approach in practice; they point to the lack of team collaboration or integration of biomedical and psychosocial expertise as being one likely barrier.

Several other papers in this Research Topic build on the science of teamwork ([12](#), [13](#)), and argue for using expertise from various disciplines to create a comprehensive plan for complex challenges. For example, a team might include an internal medicine physician bringing a biomedical perspective, a psychologist attending to the cognitive and/or emotional perspective, and a social worker addressing myriad social and logistic dimensions of the situation. Ideally each team member is grounded in a general biopsychosocial approach so they have this overall shared mental model as well as their own specific area of expertise. These papers raise issues about teamwork such as the importance of role differentiation and the need to develop a new “shared dedication” or “solidarity” across disciplines. [Sunder et al.](#) describe a team approach to providing BPS care while maintaining continuity of community mental health care in rural India during the pandemic lockdown. They note that the pivot to remote care led to increased reliance on technology and a subsequent shift in team dynamics and wellbeing. Noting the similar challenges faced by a US-based community mental health clinic during the pandemic, [Lamberti](#) wrote a commentary commending [Sunder et al.](#) on engaging new team members in the community “to build confidence and trust in healthcare professionals.” [Poleshuck et al.](#) also emphasize the advantages of engaging community members in the development of a novel collaborative team-based approach to intimate partner violence. They discuss the advantage of convening bi-weekly multidisciplinary meetings and utilizing support from a community advisory board to ensure shared goals and purpose. [Murphy et al.](#) describe a BPS informed team approach to address cardiovascular risk among patients with severe mental illnesses. Using an illustrative case-example, they note the importance of regular communication and shared goal setting to ensuring accountability of various team-members.

## Building the foundation: Training innovations in the biopsychosocial approach

Vital to any approach to implementing the BPS approach is the way we prepare ourselves and others to do the work. Training, while historically focused deeply on discipline-specific content, skills, knowledge base, and intervention, increasingly represents an important milieu in which to plant seeds for the BPS approach, and for making room within those specific interventions, for example, for considering how these domains all influence patient and family outcomes. Rosenberg and Mullin ([14](#)) describe in depth some of the foundational skills

in integration that can be incorporated into training across the professional lifespan, including in early phases of identity development and professionalization, and professional and Interprofessional continuing education throughout our careers. Funderburk et al. articulate this opportunity beautifully in their paper describing the potency of shared medical visits, conjoint appointments, and pre-session huddles in integrated primary care settings.

Training ideally focuses on core competencies of integration. These may start as additive to the discipline-specific content, but hopefully become foundational over time. Beginning with a solid curriculum rooted in the biopsychosocial approach is vital, and from that foundation, the BPS approach can propel learning around complex social systems like institutionalized racism and health disparities. Sanders and Fiscella offer a particularly sobering and instructive application of the BPS approach to teaching through an antiracist lens for clinicians serving already marginalized populations. Their work challenges us to consider the urgent need for all of us to incorporate health equity principles into our teaching and practice.

As clearly evidenced by the last several years of the pandemic, novel approaches to delivery of this training must be considered, including ones that seize opportunities to train health professionals across discipline boundaries and in venues that allow for easier access. Gils et al. describe their innovative approach to building skills to treat and support patients with persistent somatic symptoms. Their online “e-learning” modules demonstrate the feasibility of providing highly satisfying training in groups for participants across health disciplines. The potential impact of such training platforms in this endemic phase of COVID is quite clear, including ones that leverage teams and learning across professional/role-related boundaries.

The stark rise in opioid-related deaths in the US since the start of the pandemic has been a clear example of the need for more biopsychosocially-attuned clinicians and staff across the spectrum of healthcare settings, not just in substance use care facilities. Russell et al. share an innovative approach to expanding access through integrating BPS training into buprenorphine training, an intervention that not only opens

more doors to care, but also mitigates clinicians’ likelihood to apply a moral lens to patient care and to hold hope that those suffering with addiction can be effectively treated.

The COVID pandemic has only served to highlight the deleterious effects of isolation and insufficient social support for those navigating the health system and dealing with disease. The crisis brought about by the inability of our existing systems of care to meet the exponentially rising demand and need have served as an urgent reminder that health is a product of the social and contextual circumstances in which humans live, in addition to the interpersonal and psychological responses to biological conditions. This Research Topic reveals both the need and the creativity of a variety of biopsychosocial approaches to these and the many other complex health challenges experienced around the world today.

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# The Biobehavioral Family Model: An Evidence-Based Approach to Biopsychosocial Research, Residency Training, and Patient Care

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Engel's biopsychosocial model, based in systems theory, assumes the reciprocal influence of biological, psychological, and social factors on one another and on mental and physical health. However, the model's application to scientific study is limited by its lack of specificity, thus constraining its implementation in training and healthcare environments. The Biobehavioral Family Model (BBFM) is one model that can facilitate specification and integration of biopsychosocial conceptualization and treatment of illness. The model identifies specific pathways by which family relationships (i.e., family emotional climate) impact disease activity, through psychobiological mechanisms (i.e., biobehavioral reactivity). Furthermore, it is capable of identifying positive and negative effects of family process in the same model, and can be applied across cultural contexts. The BBFM has been applied to the study of child health outcomes, including pediatric asthma, and adult health, including for underserved primary care patients, minoritized samples, and persons with chronic pain, for example. The BBFM also serves as a guide for training and clinical practice; two such applications are presented, including the use of the BBFM in family medicine residency and child and adolescent psychiatry fellowship programs. Specific teaching and clinical approaches derived from the BBFM are described in both contexts, including the use of didactic lecture, patient interview guides, assessment protocol, and family-oriented care. Future directions for the application of the BBFM include incorporating temporal dynamics and developmental trajectories in the model, extending testable theory of family and individual resilience, examining causes of health disparities, and developing family-based prevention and intervention efforts to ameliorate contributing factors to disease. Ultimately, research and successful applications of the BBFM could inform policy to improve the lives of families, and provide additional support for the value of a biopsychosocial approach to medicine.

**Keywords:** biobehavioral model, biopsychosocial model, child psychiatry, family practice, family relations, graduate medical education

## INTRODUCTION

In his 1977 paper, Engel stated his belief that in order for a medical science to have a complete understanding of disease, as the underpinning for rational treatment and health care, “it would need to incorporate the patient, the social context in which he lives, and the complementary system devised by society to deal with the disruptive effects of the illness, that is the physician role and the health care system” ((1), p.132). In short, medicine needed a *biopsychosocial model* (BPS) [See (2) for an in-depth analysis of Engel’s Biopsychosocial Model in the context of paradigms, models, and theories]. Engel’s Biopsychosocial Model was based in systems theory, which assumes that all levels of organization are linked to each other in a hierarchical relationship, so that change in one affects change in the others. Thus, the model assumed that biological, psychological, and social factors were interrelated and influenced one another in both physical and mental disease. However, the BPS model itself did not include specific aspects of the biological, psychological, or social factors, nor mechanisms by which interrelation occurs (3). This lack of specificity limited critical research which would fully instantiate the model and provide guidance for adequate scientific inquiry, education, and clinical applications of the model.

## THE BIOPSYCHOSOCIAL CONTINUUM OF DISEASE

Biopsychosocial conceptualization has been enhanced by recent advancements in neuroscience with regard to specificity of the rich interplay of social stress, psyche, and soma in both physically and emotionally manifested illness (4). Research has also demonstrated the powerful role that social stress plays in emotional and physical illness (5). These scientific advances can be organized into the following heuristic framework conceptualizing the relations among physical and psychological aspects of illness [Figure 1, reformulated from (6)]. This framework illustrates the interplay of social, psychological, and biological manifestation of illness, and the pathways, and mechanisms (curved arrows) underlying these causal effects. The framework rests firmly upon the assumption that there are verifiable psychobiological mechanisms that mediate the interplay of social stress and adversity with psychological and biological factors to determine psychologic/emotional and physical illness (6). Using this framework will facilitate identification and verification of mechanisms and pathways in order to fully understand the biopsychosocial aspects of disease, and to optimally target interventions.

## THE BIOBEHAVIORAL FAMILY MODEL

One obstacle to integrated biopsychosocial care is the lack of integrative models that provide a shared language and conceptualization across disciplines. The Biobehavioral Family Model (BBFM) (7) is one model that can facilitate specification and integration of biopsychosocial conceptualization and

treatment of illness (see Figure 2). It is one of many possible biopsychosocial models. However, the BBFM prioritizes family factors based on the evolutionary assumption that the family social system serves as a buffer and means of adapting to social stress and adversity. Thus, to the extent that the family relations are functional, the family will buffer individual family members from stress; but, if family relations are dysfunctional they may exacerbate the effects of stress and adversity on an individual family member’s health. The BBFM was developed to identify specific pathways by which family relations impact both emotional/psychological and physical illness, through psychobiological pathways. The value of the BBFM is to facilitate the development of knowledge through research and apply it to training procedures, to the practice of family-based interventions, and, eventually, to family policy.

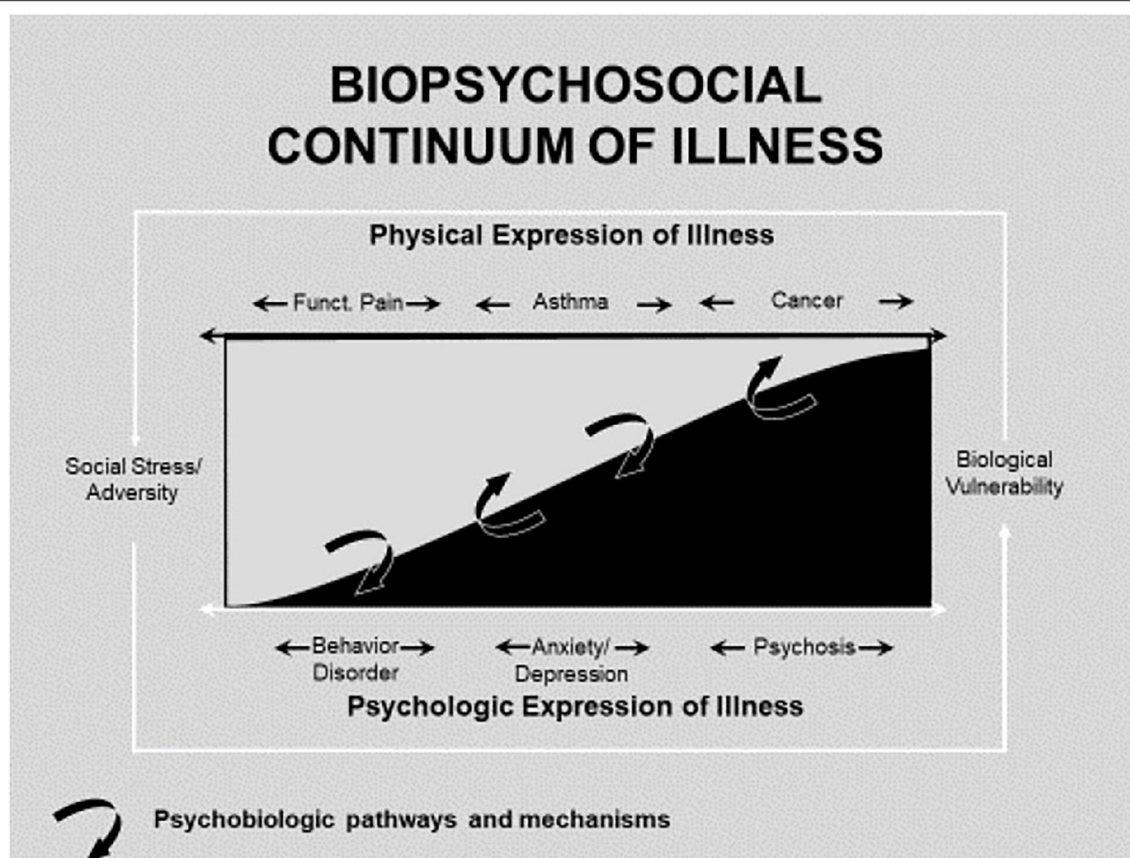
There are three aspects of the model which together are an advance in family theory. First, the BBFM is based in normative, rather than in dysfunctional concepts of family relations, so it is capable of identifying positive aspects of family relational process. Second, the model is dimensional. This means that each of its family relational constructs is conceived as a quantitative continuum. Family relational process characterized by the positive ends of the continua would suffer the effects of stress (internal and external) on the individual, whereas family process characterized by the negative ends of the continua would transmit internal family stress and exacerbate external stress on the individual family member. These two aspects provide for consideration of *both* protective and negative effects of family relational process in the same model. Finally, the constructs of the BBFM are not culturally bound, so it can be applied across ethnic groups and social class. A comprehensive presentation of the BBFM is found elsewhere (7).

The BBFM model originally focused on the child. However, the model can be, and has been, adapted to study patients across the lifespan and in various SES and ethnic groups. Explorations are underway regarding its value as a model of family influences on resilience. The BBFM incorporates specific conceptual dimensions of family relational process: (1) family emotional climate; (2) interpersonal proximity; (3) generational hierarchy; (4) parent-parent relationship quality; (5) responsivity; (6) attachment security; and (7) biobehavioral reactivity (7).

### Family Emotional Climate

Family emotional climate refers to the overall intensity and valence of family emotional exchange. It colors all aspects of family relationships, and therefore is likely a key factor contributing to emotional status and outcomes in family members. A negative family emotional climate (NFEC) includes hostility, criticism, verbal attacks, etc., and it is similar to the criticism construct of Expressed Emotion [EE; (8)]. Positive aspects include warmth, affection, support, affirmation, etc. Family emotional climate is characterized by the intensity and balance of this negative and positive emotional exchange among family members. This balance or imbalance can be construed as reflecting one aspect of family-level emotion regulation or dysregulation.





**FIGURE 1** | Biopsychosocial continuum of illness [reformulated from Miller and Wood (6)].

## Proximity

Proximity is an index of interpersonal connectedness, based on the extent to which family members share physical affection, private information, and emotions (9, 10).

## Generational Hierarchy

Generational hierarchy refers to the extent to which caregivers are in charge of the children by providing nurturance, guidance, and limit setting through strong parental alliance and absence of cross-generational coalitions (9, 10).

## Parent-Parent Relationship Quality

Parent-parent relationship quality refers to interaction patterns, which include mutual support, understanding, and adaptive disagreement (respectful and resolving) vs. hostility, rejection, and conflict. Parent-parent relationship quality sets the stage for family level emotional climate. It also has direct effects on children's emotional functioning (11), with emotional security mediating the link (12). Parental conflict is accompanied by physiologic stress responses in the exposed child (13, 14).

## Responsivity

Responsivity refers to the extent to which family members are behaviorally, emotionally, and physiologically responsive

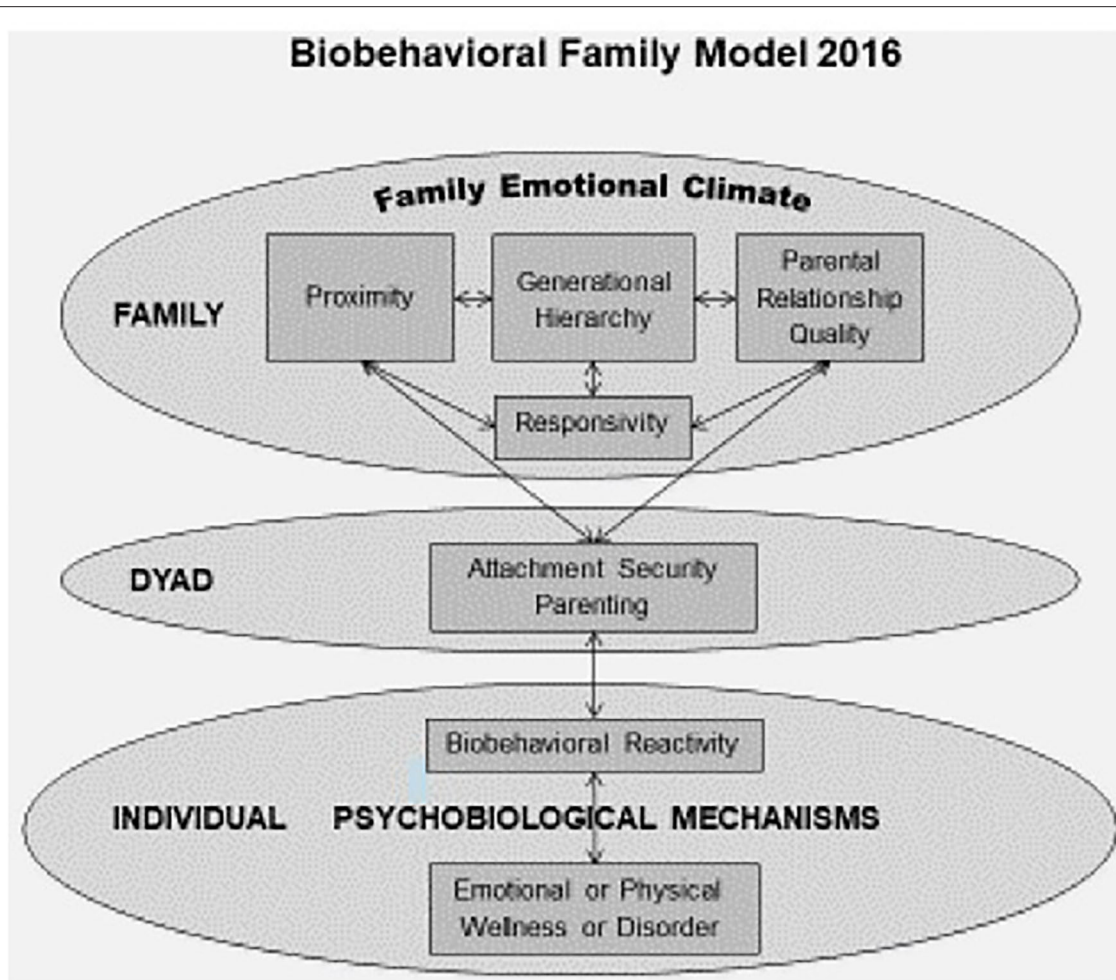
to one another. Moderate levels of emotional/physiological responsivity allow for empathic response among family members. Extremely high levels of responsivity can exacerbate maladaptive emotional/physiological resonance in the family, possibly worsening stress-influenced emotional or physical disorders. Extremely low levels of responsivity result in neglect or avoidance, leaving family members unbuffered from internal, familial, or environmental stressors. Family-wide levels of responsivity reflect family level emotion or stress regulation or dysregulation. Thus, family level emotion regulation and individual biobehavioral reactivity (see below) are inter-related.

## Attachment

Attachment refers to the biologically based, lifelong tendency of human beings under conditions of stress to seek, and receive some form of proximity (physical or emotional) with specific other persons who are perceived as protective or comforting, such that one's emotional and physiological disequilibrium are restored (15, 16).

## Biobehavioral Reactivity

Biobehavioral reactivity, the pivotal construct that links psychological to biological processes in the BBFM, is conceptualized as the degree or intensity with which an



**FIGURE 2 |** The biobehavioral family model (7).

individual family member responds physiologically, emotionally, and behaviorally to stressors or emotional stimuli (17–20). Biobehavioral reactivity is tightly linked to emotion regulation and dysregulation because it is the phenomenological outcome of the convergence of the biopsychosocial processes inherent in stress and emotion regulation and dysregulation. Chronic levels of child emotion dysregulation are expressed as child depression and anxiety (21).

Emotion regulation is accompanied by a relatively stable physiological regulation, whereas emotion dysregulation is accompanied by physiological dysregulation. Emotion regulation buffers, while emotion dysregulation transmits (or escalates) the effect of stress and emotional challenge to disease processes by way of psychophysiological pathways. Thus, biobehavioral reactivity reflects the ability of the individual to regulate the physiological and behavioral aspects of stress and emotion. All aspects of the neurophysiological stress response system (autonomic, hypothalamic pituitary adrenal, neuroendocrine systems) are underlying biological pathways and mechanisms of biobehavioral reactivity (4).

## Psychobiologic Pathways

In order for the BBFM to be a viable model to explain the impact of family on medical disease, there must be viable *psychobiologic pathways and mechanisms* by which negative family relational process cascades to biobehavioral reactivity and thus impacts disease. Several studies have identified neuro-endocrine-immune stress pathways implicated in the impact of stressors on medical disease (4). In the case of the impact of family relational stress on child asthma, it has shown that child depression, which is evoked by negative family climate and insecure attachment, is associated with autonomic dysregulation (specifically a predominance of parasympathetic/cholinergic over sympathetic reactivity to stress). Since airway constriction in asthma is partially mediated by cholinergic pathways, such predominance of cholinergic reactivity results in airway compromise in response to laboratory stress (6, 22, 23). Other studies have shown that chronic family stress impacts child asthma by way of immune pathways, specifically by altering asthma-relevant cytokine and cortisol function (24).

The BBFM model is designed to be an empirically testable, refutable model. It has proven to be usefully modifiable and widely adaptable to various age groups and ethnic backgrounds. By design, the BBFM can address family effects which either protect from, or contribute to, physically and/or psychologically/emotionally manifested disease, and identify psychobiological mediators of these effects. Intentionally, the nature of the basic framework of the model lends itself to alteration and development.

One modification is to examine the effect of parental depression on child emotional and asthma disease activity, mediated by negative parenting and child depression. In a study of depressed mothers, Lim et al. showed that maternal depression predicted negative parenting which impacted child depression, which in turn predicted worse child asthma (25). In a study of two-parent families, parental depression predicted inter-parental hostility, which predicted negative parenting, child depression, and worse asthma disease activity (26). Another study showed that single maternal caregiver depression impacted child asthma mediated by both insecure attachment and child depression (Author).

## PEDIATRIC RESEARCH IN SUPPORT OF THE BBFM—CHILDREN WITH ASTHMA

The BBFM pathway from negative family climate to insecure attachment to depression (i.e., biobehavioral reactivity) was tested in a laboratory-based family interaction study of children with asthma. Structural equation modeling (SEM) demonstrated that NFEC (operationally defined as a predominance of negative/hostile over warm interactions) predicted child asthma disease severity, mediated by insecure attachment and child depression (27). Structural equation modeling focusing on two-parent families, using the same database, showed that parent-parent negative emotional climate predicted increased child asthma disease activity mediated by negative parenting (operationally defined as a predominance of negative/hostile over warm interactions) and child anxiety and depression (26). Thus, the results of these studies are suggestive that the BBFM may be useful in specifying family-psycho-biological pathways by which family relational stress impacts child physical well-being and disease. Furthermore, the findings suggest that the BBFM, as a dimensional model, may be used to examine how family function may buffer the impact of social stress on child asthma by examining the effects of the family configurations constituted by family relational patterns at the positive ends of the BBFM dimensions (i.e. when warmth predominates over negative/hostile interactions).

## BBFM APPLIED TO ADULT HEALTH

The BBFM was originally developed to address pediatric illness. Subsequently, it has been adapted by Sarah Woods to examine the specific pathways by which family relationships impact adult health and illness. In the BBFM adaptation for adult health, family emotional climate is defined as before, but the impact

of the intimate partner emotional climate is distinguished from the emotional climate of other relationships in the family (i.e., non-intimate family relationships). That is to say, the emotional climate in the adult intimate relationship is distinguished from the overall emotional climate of the patient's relationships with other family members.

The first test of the BBFM with an adult sample explored the ability of the model to predict the effects of family emotional climate on the physical health of underserved, primary care patients [aged 18–65; (28)]. The authors found that family emotional climate (measured as family functioning) was linked to disease activity (operationalized as illness symptoms and role limitations due to physical health) via biobehavioral reactivity, specifically depression, and anxiety symptoms. In this same study, a second model operationalized family emotional climate as romantic relationship satisfaction and found that biobehavioral reactivity served as a significant link between this measure of emotional climate and disease activity [expanded to include measures of general health and pain (28)]. This project supported the application of the model to adult family members, and research in this area has since flourished.

While application of the BBFM for adults has not incorporated parent-child attachment security as an additional mediator, there have been two extensions of the operationalization of family emotional climate to include parent-adult child relationships. First, Priest et al. (29) tested the contributions of adverse childhood experiences, including abuse and neglect experienced in the family during youth, alongside measures of concurrent intimate partner emotional climate and (non-intimate) family emotional climate, on self-rated health, comparative health, morbidity, and number of prescription medications as measures of disease activity. Second, recent research has operationalized family emotional climate to include maternal and paternal affection experienced during childhood, predicting health appraisal, and number of chronic conditions over 20 years (30). Expanding the definition of the family emotional climate construct to intentionally incorporate the emotional climate of family relationships experienced in childhood, intimate partner relationship quality, and concurrent non-intimate family emotional climate (including parents' relationships with their own children) constitute clinically relevant extensions of the BBFM explanatory model.

Both pediatric and the adult BBFMs posit, and test, biobehavioral reactivity as a critical mechanism linking the effects of emotional climate on health. Biobehavioral reactivity is operationalized as emotion dysregulation (e.g., anxiety and depression) for both models, and is linked to disease activity via the impact of psychophysiological stress reactions. However, research in adults has extended the operational definition of biobehavioral reactivity to include allostatic stress pathways, with allostatic load (31) as an index of biobehavioral reactivity [e.g., (32)]. In addition, the model has been extended to test the contribution of health behaviors, influenced by family emotional climate and in concert with biobehavioral reactivity, to impact adult health outcomes [e.g., (33)].

Many studies have now substantiated the role of both intimate partner relationships as well as non-intimate family



relationships in understanding the impact of family on health for adults [e.g., (33, 34)]. Though both operationalizations of family emotional climate—the positivity or negativity, and intensity, of intimate partnerships *and* of non-intimate family relationships—have been significantly linked to disease activity in tests of the BBFM, studies have tended to support more powerful links for non-intimate family relationships, especially when negative and intense [e.g., (29, 35, 36)]. In addition, an application of the BBFM tested with a national, representative, epidemiological U.S. sample operationalized family emotional climate as marital strain and family support, while testing social support received from friends as an additional, contrasting factor (37). The former two measures (assessed as demanding, critical, unreliable, or irritating partner behaviors, and being able to rely on and open up to relatives, respectively) were supported as operationalizations of family emotional climate and were linked to disease activity via biobehavioral reactivity. Friends' support, however, was not significantly associated with health, directly nor indirectly. This finding highlights an advantage of the BBFM over more general models of relationships and health: the construct of "social support" remains loosely and variably defined; this lack of specificity often interferes with replication and application of these findings, and overlooks the specific and powerful impacts of family relationships. The BBFM lends the specificity necessary in order to develop family relational targets for intervention.

Woods et al. (30) subsequently expanded the concept of family emotional climate. Specifically, the authors found four distinct categorizations of family emotional climate, i.e., positive, negative, ambivalent, and indifferent climates, each predicting different outcomes. Their models indirectly linked a NFEC (marked by high strain, low support, and low parental affection) with worse disease activity (i.e., health appraisal) 20 years later via biobehavioral reactivity (i.e., negative affect reactivity reported via daily diary reports) at 10 years. Further, an ambivalent family emotional climate (marked by high strain plus high support) was directly linked to greater morbidity two decades later.

## Expanding the Construct of Biobehavioral Reactivity

Woods expanded the concept of biobehavioral reactivity beyond depression and anxiety for adults [reflective of emotion dysregulation via both affective and physiological symptoms; (29)] to include negative affect, defined as subjective distress and negative emotional states such as nervousness, irritability, fear, and frustration (38). Research also suggests physiological changes, such as cortisol and C-reactive protein response, and cardiovascular reactivity, for example, are components of negative affect reactivity (39, 40). Recent BBFM research used daily diary reports of negative affect related to stress exposure as an operationalization of biobehavioral reactivity. Specifically, Woods et al. (30) incorporated participants' reports of the frequency of 14 negative emotional states (e.g., restless, hopeless, lonely, ashamed) in response to specific stressors (e.g., arguments, work or school stress,

discrimination) across 8 days into a test of the BBFM, finding that negative affect reactivity significantly mediated the link between a NFEC and disease activity (i.e., health appraisal) 20 years later.

Woods and colleagues have also incorporated tests of allostatic load as measures of biobehavioral reactivity conveying the effect of family emotional climate on disease activity for adults [e.g., (29)]. Priest et al. (32) found support for a broad-spectrum index of allostatic load in a cross-sectional test of the BBFM, whereby a NFEC (but not a negative intimate partner emotional climate) was significantly associated with disease activity (i.e., morbidity, prescription medication use) via both depression and anxiety, as well as allostatic load (comprised of indices of cardiovascular health, metabolic lipids, metabolic glucose, inflammation, and parasympathetic nervous system functioning). However, whereas Woods et al. (30) found support for negative affect reactivity as an operationalization of biobehavioral reactivity, the authors did not find support for allostatic load as a mediating pathway in their longitudinal test of the BBFM. It is possible that more fine-tuned quantifications of biological aging—patient-level measures of aging that compare aging adults' biomarker results to peer populations—may be more attuned to capturing variation in psychobiological pathways impacted by stress than static measures of allostatic load (41, 42).

Lastly, though not theorized as a pathway to health in the pediatric BBFM, tests of the model with adults have incorporated health behaviors as a potential additional mediator, alongside biobehavioral reactivity. Though emotional climate retains significance as a pathway to disease via stress reactivity, health behaviors have been tested as an additional pathway through which emotional climate affects physical health—and, as a variable that is correlated to (and impacted by) biobehavioral reactivity. In other words, the valence and intensity of relationship quality for adults has the potential to both discourage (or support) healthy health behaviors, as well as to potentiate (or decrease) stress reactivity. Thus, variation in adults' biobehavioral reactivity is theorized to covary with (to impact and be impacted by) health behaviors, contributing in turn to disease activity. Initial tests have found some support for the addition of health behaviors to the model: Roberson et al. (33) found stress-eating and exercise (both reported 10 years post-baseline) each served as significant links between baseline intimate partner emotional climate (i.e., marital strain) and disease activity (i.e., morbidity, prescription medication use, health appraisal) 20 years later, alongside the significant mediator of depression and anxiety (also measured at 10 years).

## Cultural Moderating Factors

The BBFM provides a structure for examining cultural differences in the effects of the BBFM pathways. For example, Priest and Woods (43) found that disease activity (i.e., morbidity and prescription medication use) of Latino Americans was predicted by a more NFEC, mediated by greater biobehavioral reactivity (i.e., anxiety and depression); the same pathways were supported for a more negative intimate partner emotional climate. Interestingly, the authors tested nativity status as a

moderator of the BBFM's pathways, finding a significant direct pathway between family emotional climate and disease activity for U.S.-born Latinos which was non-significant for foreign-born participants. These results suggest that non-intimate family relationships may affect the physical health of U.S.-born Latino adults in ways not fully explained by the study's measure of biobehavioral reactivity. The study's findings may also imply that acculturation and health behavior play important mediating roles in the model, in keeping with other research regarding nativity-influenced health differences [e.g., research on the immigrant paradox; (44, 45)].

More recently, Priest et al. (36) tested the BBFM with a sample of African American adult participants in the Midlife Development in the United States Milwaukee project, incorporating considerations of discrimination to test its influence on family emotional climate, defined as family support vs. family strain. First, the authors found that greater discrimination was associated with worse family support and greater family strain; second, worse family support served as a significant mediator linking increased experiences of discrimination to worse biobehavioral reactivity (i.e., worse self-rated mental-emotional health). It is noteworthy that the authors also found that lack of family support (but *not* family strain, nor intimate partner support or strain) was associated with decreased biobehavioral reactivity (i.e., better self-rated mental-emotional health). It is possible that the BBFM could be expanded to incorporate considerations of social determinants of health—with discrimination as a powerful example—which impact health via the influence of these contextual stressors on family functioning, and stress.

## IMPLEMENTATION OF BIOPSYCHOSOCIAL TRAINING AND PATIENT CARE IN MEDICINE FACILITATED BY THE BIOBEHAVIORAL FAMILY MODEL

One challenge to implementation of the biopsychosocial model in medical training is the lack evidenced-based models that not only emphasize the importance of the interconnection of biological, psychological, and social aspects of health and illness, but also specify pathways and mechanisms by which these factors influence one another. Such a model lends credibility to the biopsychosocial approach and a common language and guiding model for teaching and clinical assessment and intervention. We will present below two applications of the BBFM in residency and fellowship training (Authors, in Family Medicine Residency, and Authors, in Child and Adolescent Psychiatry Fellowship).

## APPLICATION OF THE BBFM IN A FAMILY MEDICINE RESIDENCY PROGRAM

Though primary care training stipulates a focus on biopsychosocial and behavioral health education, these curricula frequently fail to cover family systems in sufficient depth. Family

medicine is an example of a discipline whose trainees report educational deficits in regard to family systems, and often lack exposure to couples and family therapy (46). This is important because, while it is well-recognized that patient illness impacts the family, it is also the case that family relationships impact the patient's illness (and response to illness). Primary care training that uses a systemic orientation to teach about families and health highlights this circular, mutual impact of patient disease on family relationships, and vice versa. Specifically, systems theory—the basis for family systems—is distinct from ecological or contextual theory: while each promote consideration of nesting, hierarchical levels of human environments, the latter may emphasize linear pathways of influence between any two adjacent systems, while systems theory postulates recursive, mutual impacts of the levels on one another via complex interactions. Thus, a family systems orientation is imperative in primary care in order to view all patients biopsychosocially, in the context of their families and communities, continually influencing *and* being influenced by the systems within which they are nested [and which are nested within them, i.e. physiological systems; (47)].

The BBFM model, being empirically tested, provides evidence for the impact of family relationships on individual health. Thus, it offers compelling justification for understanding a patient's disease in the context of family relations, which then informs their diagnosis and treatment. This is especially powerful in primary care: applying the constructs of the BBFM in primary care settings facilitates a clearer understanding of family-health connections for a wide range of patients and conditions. Specifically, the BBFM used in primary care, (1) systemically contextualizes patient illness, (2) delineates specific targets for assessment, (3) directs interventions toward areas that are maximally effective, and (4) supports primary care trainees in achieving competency in the prior three areas (i.e., systemic, family-oriented thinking, assessment, and intervention). The model provides the theoretical, evidence-based framework needed for the necessary paradigm shift in primary care, and resident training, toward family systems. Presented here is one example of how the model may be applied in family medicine residency, a setting in which training is embedded within clinical care.

## Training

In order to promote a family systems paradigm, and the ability of residents to think systemically, it is necessary for family systems training to be embedded within resident education broadly, rather than isolated as part of a single course or rotation (48). Educators teaching family-oriented care also require a “translation process,” and often must re-language complex relational and systemic concepts into a language familiar to, and easily understood by, physicians. The BBFM can help to achieve both aims: first, to guide the organization of resident psychosocial training, and to teach, demonstrate, and clarify why families are important for the work of primary care physicians. Second, the model serves as a clear, pragmatic map for educators engaged in such translation processes, as they interpret complex close

relationships into case-specific content that is applicable to, and by, resident learners.

### Foundation in BBFM Concepts

First, BBFM-guided training can be achieved via didactic exposure to research evidence for the influences of family and stress on illness. To serve as one example: primary care trainees are often taught a variety of aspects of *health behavior change*, including (a) the impact of specific health behaviors as well as (b) interventions to promote patient motivation and behavior change. To revise curricula specific to health behaviors, the BBFM concepts can be translated and applied to teaching the mechanisms whereby social networks influence health behavior, and thereby impact health outcomes. In other words, an educator can translate “*family emotional climate and the mediating link to health via biobehavioral reactivity*” as “*family support and family strain impacting patients’ stress reactivity and mental health*,” as well as their health behavior. To demonstrate empirical support for this connection, research substantiating the BBFM’s pathways can be described, explaining links between family relationships, depression/anxiety, and smoking, alcohol use, exercise, and binge eating [e.g., (33)]. Lastly, basic health behavior change interventions that are familiar to residents can be discussed, and then expanded upon to a family-oriented, systemic perspective. For example, educators can review the importance of assessing patients’ readiness for change [e.g., from a motivational interviewing approach; (49)], including how patient “stress reactivity” can stifle confidence and behavior change enactment (50). Then, residents can be taught how to assess whether patients’ family relations are possible barriers to change or are sources of support for disease management, thus highlighting the impact of family members’ own health behaviors for promoting (or impeding) patient behavior change. Finally, lecture-based teaching can include using case-based examples or even role play [methods likely to resonate well with adult resident learners; (51)] modeling how to invite a patient’s family into a behavior change intervention, emphasizing the importance of leveraging this critically important support network for improving patient adherence. This type of practice facilitates learning that can then be applied in the clinical space. Overall, family-oriented primary care first requires the recognition of the importance of families to health, and the impact of illness on family process. The BBFM can aid in encouraging a view of family members as important, worthy stakeholders, *and* contributors to the clinical process—that is, families as both resources and, at times, rate-limiting steps to change.

In addition to incorporating family emotional climate into teaching about specific clinical topics relevant to primary care, the successful translation of the BBFM framework for residents may advance their ability to think systemically. In other words, learning specific examples of recursive associations between family relationships and patient illness via a longitudinal curriculum approach (52) will likely generalize to residents being able to think biopsychosocially and in terms of hierarchy, responsivity, boundaries, and feedback loops (rather than merely a linear cause-and-effect relationship). Once the links between

families and health are taught conceptually using examples, the content needs to be further mastered in the context of clinical application. The use of experiential training can ensure trainees recognize how families impact a patient’s health, are able to assess relational process, and can intervene systemically.

Last, the application of the BBFM can be extended to residents’ introspective training in order to increase their understanding of their own experiences of health and illness, and thereby increase their empathy for patients.

### Perception

The BBFM is useful in guiding residents’ observation and perception of family relational process as it relates to a patient’s disease or disorder, as well as guiding assessment of the psychosocial impact of illness on the patient and their family. One way the model aids resident perception is via use of a checklist with behavioral examples of the BBFM dimensions. This type of checklist can be used to facilitate residents’ observations of family emotional climate in a patient’s family. Such guides for observation should use terminology familiar to physicians in order to remove a mental leap doctors need to make to focus on family functioning. For example, if working with a patient and a family member, emotional climate becomes best conceptualized as *strain* (conflict, inconsistency, neglect) vs. *support* (openness, reliability, warmth, affection) in the dyad. Residents can also be guided to observe for power dynamics in the dyad, noting who is responsible for decision-making, or how the dyad negotiates shared responsibilities (e.g., parenting, housework, financial planning). Directing the resident to observe the qualities of this relationship ultimately increases the depth of their observation, and may facilitate residents moving to direct assessment.

### Assessment

Though the BBFM is not a therapeutic model, it is a well-defined theoretical foundation that can support therapeutic skill in primary care, beginning with assessment. For example, the BBFM-informed observational checklist described above can also be used as a map for screening and interviewing. First, beyond listening for cues regarding relationship quality, or observing family relationships in the exam room, physicians can be taught to ask basic questions to gather key information regarding support and strain among family members. As the BBFM conceptualizes both adaptive and maladaptive family functioning, it can guide trainees to assess both positive and NFEC, including praise vs. criticism, adaptability vs. passivity, flexibility vs. rigidity. Residents can also draw out patient-family member dyads and invite them to talk together about how they understand the doctor’s recommendations, how they are working together to achieve treatment adherence, or how they would like to receive support from one another for lifestyle changes. To assess *responsivity*, physicians can verbally affirm observations of within-family empathy, ask about experiences of denial, secrecy, or isolation in the face of a new serious illness, or assess family-level emotion dysregulation due to worsening disease. The structural dimensions of family emotional climate can also be translated into patient assessment in primary care.

*Proximity* (i.e., connectedness, caring, empathy, knowing what a family member is experiencing) can involve physicians asking patients about how they share their emotions with their family, or how they show one another affection. *Generational hierarchy* (i.e., power dynamics) can be evaluated during well child visits, demonstrated by parents' limit-setting or co-parenting. Maladaptive couple hierarchy is another possible area to assess, including power imbalances within a romantic relationship, which may increase stress and thus contribute to a patient's worsening disease activity.

As primary care physicians provide the bulk of mental health care in the U.S. (53), they are well-positioned, and often well-trained, to assess for stress, depression, and anxiety. However, an expansion of this training is needed to facilitate an understanding of stress reactivity as a mechanism by which the family emotional climate may be tied to disease; i.e., whether a patient's family emotional climate (i.e., stress or strain) is contributing to depression or anxiety in the patient. Having assessed family emotional climate variables, the family-stress-disease links should become more apparent than when physicians solely assess mood. The care of postpartum mothers and their infants (a form of family unit commonly encountered in primary care) provides an example of how this may be applied. Residents can be trained to assess for parents' relationship quality and spousal support, and how this may impact the mother's recovery after childbirth and ability to provide newborn care. Residents can also assess attachment security in the parents' relationship, and associations with maternal/paternal-infant attachment—another evidence-based dimension of the BBFM. The closeness and safety of these relationships may be tied to the newborn's physical development and demonstrating expected milestones during infant well child appointments. Conversely, a resident can assess whether an infant with a complicated neonatal course creates additional stress with which new parents may struggle to cope; this may be independent of the risk of postpartum depression, which is regularly screened for in the primary care setting. This example also highlights the recursive nature of associations between family and health; namely, that not only can family relationships impact health via stress, but also that illness, and related distress, impacts family. Because causal effects are presumed to be reciprocal in the BBFM, the model can be a useful map for trainees to observe the impact of illness on the patient's emotion regulation (i.e., biobehavioral reactivity) and the patient's family's relationships. Though some families may react to worsening disease with acceptance, open discussion, connection, or agency, others may buckle with isolation, renewed rifts, withdrawal, or resentment (54).

Although genograms are not a part of the BBFM, they importantly extend the utility of the BBFM as a guiding model. Genograms may be used to enhance residents' reflective ability and increase their awareness of family-health connections through examining systemic patterns in their own families-of-origin related to health and healthcare. Residents can extend the recognition of these patterns to discuss how patterns of family response to illness may be connected to their own development as a physician, as well as how they approach the patient-physician relationship. Though infrequently taught in family medicine

residency programs (55), the genogram can powerfully support the development of empathy, especially if first applied to oneself. Lastly, the use of a genogram in direct patient care to assess family patterns can be taught in conjunction with the practice of gathering family health history, a critically important activity for documenting patients' disease risk (56).

The assessment of a patient's family emotional climate provides key insight into whether relationships may be contributing to the patient's disease or disorder, and if so, by what means: e.g., interfering with vs. supporting health-promoting behaviors, or contributing to disease activity through stress pathways or emotion dysregulation vs. soothing or modulating stress. Boosting physicians' abilities to observe relational processes first, and then linking them to health and illness via the pathways of the BBFM, increases the practice of thinking systemically as well as considering alternate aspects for intervention, aside from a limited focus on the "usual suspects" (e.g., an individual patient's medication adherence, diet, exercise).

## Intervention

Interventions used with patients and their families in primary care must first be organized around time considerations, with a priority on brevity. However, brief interventions need not sacrifice a family systems orientation. The BBFM also helps locate the most efficient route to effective brief intervention.

In training residents to intervene, it can be helpful to first focus on developing basic family interviewing techniques (57). The use of reflection statements can first serve to validate patient and family experiences, while the successful use of reframing statements can systemically shift a family's paradigm toward understanding their relational process and its influence on family members' well-being. As described above, the BBFM is designed to encompass aspects of relational functioning that promote resilience, as well as areas of vulnerability. It is thus helpful in identifying strengths, a core interviewing skill that can highlight what is working within the family, rather than exploring deficit alone. Example questions residents can ask to solicit the above include, "who else knows you are struggling?" and, "how do they support you taking care of yourself?"; these may help patients understand the power of their social network. This also leads the physician to explicitly assess who is supporting the patient, and who may be undermining them, which facilitates the active inclusion of supportive family members to strengthen those ties. In other words, this strategy identifies patients' social supports, but also whom, in the family, it would be most useful to engage in primary care visits. The first step in family-centered interventions is to determine who in the family would be most important to involve in care, either to mitigate negative/maladaptive relationship effects or to facilitate more supportive, adaptive ones.

Recruiting supportive family members to attend appointments, and meaningfully engaging them in the patient visit, adds a powerful, but brief, intervention to the physician's therapeutic toolkit. Patients may be more likely to understand treatment recommendations, and more apt to discuss difficult topics with their provider, when a support person joins their visits (58). Patients can also be encouraged to disclose worsening



depression or anxiety to supportive family, and to open up to safe, empathic family members who can provide warmth and decrease isolation. We find that family members often intuitively sense the patient's distress or disease may be worsening but may be unsure how to offer their help. We therefore encourage physicians to directly reflect this possibility to the patient, and suggest a family pattern of dancing around issues of privacy and sensitive health issues, while simultaneously wanting more closeness. Family interviewing techniques applied during conjoint medical visits can include the resident assessing patient and family health beliefs (and whether they're aligned), cultural influences on health behaviors, family members' fears regarding the patient's disease, family members' perceptions of the patient's coping with a new diagnosis, or the impact of an illness on the family's functioning (59).

Family member attendance also necessitates a shift in point of care interventions to be intentionally more family-oriented. Brief family-oriented interventions in primary care can be easily adapted from existing interventions commonly used to promote patients' behavioral health. For example, motivational interviewing [frequently considered a powerful approach to shifting health behavior in primary care settings; (49)] can be adapted to be relational (60) via including the family in brainstorming ideas for change, assessing the family's support for behavior change, assessing family members as potential barriers to change, and scaling the family's buy-in and confidence in the intended change. Collaborative treatment planning with patients—discussing pros and cons of treatment options, developing next steps that reflect patients' values, etc.—can be easily shifted to engage family members in the process, thereby enhancing the likelihood of adherence and success (59). Finally, the BBFM, by promoting specificity and efficiency, may facilitate current movements toward single session mental health care in the context of primary care [e.g., (61)].

## APPLICATION OF THE BBFM IN A CHILD AND ADOLESCENT PSYCHIATRY FELLOWSHIP PROGRAM

In the United States, general psychiatry residents are typically introduced to a systemic biopsychosocial model of psychiatric disease, but are not allowed or encouraged to practice this way. However, child and adolescent psychiatry is much more cognizant of developmental, family, and socio-cultural contributions to child and adolescent psychiatric disorders, and thus there is a natural appreciation of the biopsychosocial model. However, there is a paucity of explanatory models that demonstrate how these complex processes interact to the benefit or detriment of the child's development and emotional functioning. Most urgently, child and adolescent psychiatry (CAP) fellows need a way to understand the child and adolescent in the developmental and relational context of their family, since the family is the most impactful, for better or worse, social context of the child. The BBFM is a model that can serve as a comprehensible map with which to navigate the complexity of family influence on the child and adolescent. We have developed

a training module for our child and adolescent psychiatry fellows using the BBFM to provide basic conceptual tools for assessing and intervening with family relational process in order to support child and adolescent treatment goals.

The “Family Relational Assessment and Intervention” training protocol is devised of an annual 5-h didactic introduction to the basic principles of family systems theory and practice, followed by a biweekly 2-h clinical application seminar occurring over 6 months. There are two supervisors, a child, adolescent and family psychologist and a child and adolescent psychiatrist, working with 3 first year CAP fellows and 3 second year CAP fellows. In the didactic sessions, we contemplate the complex meanings and functions of “family.” We introduce the essential assumption of reciprocity of effect between individual and family levels of experience and behavior. We introduce child developmental staging via Eric Erikson's (62) Eight Stages of Man and Josephson's family psychodynamic developmental approach (63). We elucidate how these developmental stages shape family stages of development (64). Finally, we examine cultural aspects of family function, and incorporate the consideration of the vulnerability of families of minority and disadvantaged status. Broadly, we work to establish that a competent child and adolescent psychiatrist must be skilled in understanding and working with families. We help them understand that, more often than not, when a child or adolescent is struggling despite the best of treatment intentions and delivery, family challenges are often at the root, and must be addressed. And just as CAPs need to utilize their skills in individual psychotherapy modalities to help struggling patients get moving again, they can and must utilize family assessment, and intervention skills to help struggling families get unstuck to the benefit of their patients.

We introduce the BBFM as a map devised of specific dimensions with which to focus assessment of family function in relation to the child. We introduce the BBFM model as described above. However, we refer to it as the “Biobehavioral Family Model of Vital Signs” in order to emphasize that the dimensions described are essential to be observed and evaluated in any psychiatric evaluation of a child or adolescent. We renamed the technical term “proximity” to “care and connection” and “hierarchy” to “parental authority” because those are more familiar concepts but synonyms for the original terms. We translate our customary family systems terminology into terms which are more familiar and comfortable for medically trained residents. Overall, this helps CAP fellows to be able to understand not just that a family is dysfunctional, but how they are struggling and how one might intervene to help them. We do not use the term “systemic” but instead point out and help them observe the mutuality of causal effects of family member interactions, and the impact of sequential patterning of interactions. Our training program teaches and requires “biopsychosocial” psychiatric evaluations as a basic format, and we incorporate a BBFM evaluation to help fellows characterize their observations and construct an accurate “family relational” formulation which incorporates the aspects of the BBFM dimensions that are contributing to the child's difficulty.

The clinical application of the Family Relational Assessment and Intervention module occurs in the form of group



supervision, live and video recorded. In order to assist the fellows in learning to observe and perceive patterns of family interactions so as to characterize the BBFM aspects of family function, we use a standardized “Family Process Assessment Protocol” (65). The Family Process Assessment Protocol was originally developed for Wood’s family and child asthma laboratory-based research described above. The results of these studies demonstrate the validity and utility of this assessment device in characterizing dimensions of the BBFM (66). The first year CAP fellows conduct these assessments and write BBFM informed assessment evaluation. The second year CAP fellows observe these assessments and contribute to the family relational formulation and treatment planning. On alternate meetings the second year CAP fellows invite families in treatment for live group supervision and discussion using a one-way mirror. In addition, if schedules require, the supervisor and fellow meet at an alternate time and record assessments and interventions in order to bring them to the bi-weekly meetings to review and discuss.

## The Family Process Assessment Protocol

Child and adolescent psychiatry fellows identify families of children whom they think would benefit from the family clinical assessment. They recommend to the families that they come to the clinic to “participate in a series of discussion tasks in order for us to learn more about how your family works and plays together.” The fellow explains that “this will help us to better understand you and your child, and therefore learn how best to help your child.” They further explain that “we work in consultation teams, so we will be observing your discussions from behind a one-way mirror.” The supervisor and non-interviewing fellows observe from behind the mirror as the supervisor points out patterning of interactions and engages the fellows in describing what patterns they are observing. While there is no intentional intervention provided during these assessments, we focus on the “family vital signs” as a framework for what specific dynamics to observe and to help fellows consider possible future interventions. We also help fellows appreciate, through observing the FPAP, that any guided, supportive family discussion can be, in and of itself, a therapeutic family intervention.

The first-year fellow treating the child conducts the protocol, presents the instructions for each task, and returns to behind the mirror to observe the family’s discussions. The discussion tasks each last 5–10 min and are designed to elicit a range of emotionally tinged interactions. The fellow presents the discussion task to the family explaining that he or she leaves “in order not to distract the family from their own discussions but will be observing.” Tasks: (1) invite the family to build a house of cards; (2) have the child present a difficulty he or she is having to the family for their help; (3) have the child tell the family the story of something that currently, or in the past, made them sad; (4) request that the parents and child discuss and resolve a previously identified disagreement; (5) have the parents (if there are two) discuss and resolve a previously defined disagreement; (6) ask family members to go around, one at a time, and say what they like best about each family member, and about the family as a whole.

At the end of the family discussions, the supervisor and fellow construct brief feedback regarding strengths observed and one or two ways of relating that need to change in order to support the child’s recovery. The fellow then provides this feedback to the family. For example, based on the BBFM dimensions, the fellow might note, “your family is clearly warm and supportive of one another (family emotional climate), and clearly your child (the patient) looks to you parents for reassurance and guidance” (secure attachment). “But mom and dad unintentionally undermine one another’s authority because they have very different parenting styles” (weak parental alliance). “This allows your child to ignore your instructions and be defiant (for a child with behavior problems).” Often, if invited to share their own observations, family members will themselves identify these relational challenges even before the fellow provides feedback. The fellow invites further questions from the family and explains that he/she will assist the family in working on these changes and address other relationship needs in subsequent intervention sessions. The supervisor provides ongoing supervision of the future family relational interventions. The patterns observed during the family protocol help the fellow to construct the BBFM evaluation, using the BBFM model and definitions (above) to develop his or her formulation of the family’s contribution to the child’s strengths and difficulties, and to devise recommendations for intervention. The supervisor provides instructive comments, edits and suggestions for the BBFM evaluation.

Once the first-year fellows become proficient in using the BBFM as a map guiding the observation of “family vital signs,” they naturally begin to observe other family relational patterns that are relevant to the child’s difficulty, or that can be tapped to support the child’s improvement. The first-year fellow generally continues intervention with the family that s/he brought into the family assessment protocol, while the family supervisor continues supervision on the case. In their second year, fellows identify at least one additional case in which they seek live supervision from one of the supervisors. These cases are live supervised or recorded and are brought to the group clinical supervision to provide clinical material for discussion of strategies for intervention. Basic intervention strategies are taught targeting dimensions of the BBFM. For example, (1) facilitating positive *family emotional climate* by redirecting negative interactions; (2) interrupting interactions reflecting poor *parent-child proximity or connection*, as when parents are not listening to the child and the child is escalating, by asking that the parent slow down and listen to the child and then reflect back to the child what the parent is hearing the child convey; (3) reframing highly reactive and hostile behavior as defensive and reflecting sadness and feelings of dismissal or rejection (signs of *insecure attachment*); (4) redirecting parents if they show *poor parental alliance* by conveying opposite messages to the child by asking them to talk with one another to sort out the different ways in which they are responding to the child; (5) interrupting, and pointing out interactions in which a parent is undermining the other parent’s instructions to the child, i.e., *weak parental hierarchy*. These examples reflect family systemic interventions, but are not exclusive. In general, these interventions interrupt and redirect

maladaptive (based on BBFM concepts) patterns of interaction to those that are consistent with the positive aspects of the BBFM model. There are many other models of family systemic intervention that are consistent with the BBFM (67).

There are many challenges to the success of this approach to training in family assessment and intervention. It is often difficult to schedule everyone in the household to come in at the same time (we typically start with both parents or caregivers, if they are living in the house, and children over 5 years of age living in the house). If the group supervision time slot cannot work, we offer another appointment and the supervisor provides direct supervision of the assessment and/or ongoing therapy. These sessions are then recorded and brought to group supervision.

Another challenge is in engaging fellows in an area in which they are quite unfamiliar and uncertain. It is helpful to avoid language that is unfamiliar and to translate concepts into terminology that they find comfortable and consistent with their training. The most important inducement is for the fellows to be able to better understand the “how” and “why” of complex cases, and feel increased self-efficacy in being able to help untangle some of the challenging psychosocial contributors to a child’s dysfunction. To support fellows in learning these complex skills, the supervisor must be readily available to provide direct support to the trainee throughout the learning process.

The clinical context of the training can be a challenge as well. Training often occurs in clinics or service centers where services are provided by a variety of professions, including social workers, psychologists, counselors, and nurse-clinicians. In these settings, child and adolescent psychiatry fellows are in high demand to provide psychiatric evaluations and medication recommendations and follow up. Thus, time must be protected so that they can carry psychotherapy cases that would appropriately require family assessment and intervention. In our training site, our CAP fellows frequently conduct Family Process Assessment Protocols for the patients of other clinicians who have requested a medication assessment from them. They explain that it is important to evaluate the patient in the context of his or her family, and they propose a family assessment. However, if the clinician explains that they have assessed the family and are currently engaging the family in the child’s therapy, the fellow will conduct the psychiatric evaluation and treatment, relying on the clinician’s report of family functioning. Alternatively, if the clinician agrees and the fellow conducts a family assessment, the clinicians are provided with a copy of the BBFM evaluation along with the usual psychiatric assessment and treatment recommendations. Often we will invite the clinician to observe the Family Process Assessment Protocol. This serves to build relationships of trust among the fellows and the clinicians, and it provides clinicians with opportunities to expand their perspective on the role family relations play in child emotional, psychological, and behavioral disorders. We also are developing a family consultation service for our clinicians, where we will conduct a Family Process Assessment Protocol for them, so that they can have that information to inform their work. When we have done this in the past, collaborations often develop, with the clinician focusing on individual intervention and the fellow focusing on family relational work.

This year the coronavirus pandemic precluded in-person family assessments and interventions. We adapted to this challenge by employing telemedicine technology. In order not to overwhelm the families and the fellows with the intensity of group online observation of telemedicine interviews, we limited the assessments and interventions to one fellow and the supervisor. We recorded the session, with family permission, and used the recordings in the group supervision seminars to observe patterns of interaction as they related to the child’s problems, discussed the interventions made and the effects they had, and planned for additional interventions for future sessions. There are certain advantages to this method, some of which may be adapted to telemedicine-based child and adolescent behavioral health: (1) it is easier to schedule the families in their homes; (2) it is very graceful to make on the spot supervisory suggestions via the private chat option in telemedicine technology; (3) we can review the recorded session in group supervision, allowing the flexibility to pause a session in order to observe, reflect, and understand the therapy in the moment, which is an efficient teaching strategy. In addition there is the opportunity to ask the fellow (or supervisor) about his or her purpose in given interventions. There are also significant disadvantages to the telemedicine approach. Most prominent are challenges in technology in the home which can cause degraded audio or visual quality; keeping the family within view; the personal awkwardness of seeing oneself on the screen; by the relatively impersonal feel of the method compared to in-person therapy; and by the limits it imposes on the clinician to be able to control escalating sequences of family conflict, which are more easily interrupted and diverted in person (the technology prioritizes the current speaker and it can be difficult for the clinician to interrupt).

The take-home message is that challenges to teaching family assessment and intervention in the context of child and adolescent psychiatry training can be overcome with strong supervisory commitment and close connection to each fellow, and flexibility and variability in formatting the experience. Although working within health care systems that appear to primarily value the child and adolescent psychiatrist as “prescribers,” the children, adolescents, and families we are asked to help are often the most impaired and in need of comprehensive assessment and treatment. At his or her core, the child and adolescent psychiatrist needs to be able to formulate a deeper understanding of what is happening in a child’s life that results in impaired functioning. In this context, training and embracing the BBFM as a framework to assess and intervene with struggling families provides CAPs both with a way to help these most impaired of children and families, as well as a way to reclaim a broader role and skillset.

## THE LEADING EDGE: FUTURE DIRECTIONS FOR THE BBFM

The BBFM’s specified pathways provide multiple avenues for future research, training, and clinical directions. For example,

including temporal dynamics and developmental trajectories in the model would enrich and extend its scope and predictive power. This would be useful from a life course perspective, as well as for modeling disease trajectories over a period of aging. The BBFM may also be of heuristic value in extending testable theory of family and individual resilience, which would support key prevention strategies. The inherent culturally flexible constructs of the BBFM makes it useful for examining causes of health disparities, and potentially to discover family patterns which may improve contributing factors including patient disease self-management. Additional research is needed to identify how societal contextual stressors contribute to the psychobiological mechanisms linking family emotional climate and disease activity identified by the model. Ultimately, research and successful applications of the BBFM could inform policy to improve the lives of families.

Though Engel's BPS model presented a critical advance for medicine, its application has been limited by its lack of specificity, constraining the model's ability to guide research and clinical practice. Further, the BPS model does not provide a well-defined language that functions across disciplines, which is necessary to facilitate integrated care. The BBFM, however, provides a specific biopsychosocial conceptualization for the study and treatment of illness in families, while acknowledging both the protective and negative impacts of family process

for health. The empirical evidence supporting the model's theoretical underpinnings ultimately lends support for Engel's BPS approach. The identification and operationalization of specific, testable constructs, and mechanisms of effect provides a guide for family-based research, training, and clinical care. The continued application and modification of the BBFM will further serve to enhance the implementation of BPS theory in medicine. Our hope is that in presenting this model, others will find it similarly useful in developing innovative research, training opportunities, and practice approaches. In addition, we recommend that the BBFM serve as a prototype for other multi-level, systemic, biopsychosocial modeling.

## AUTHOR CONTRIBUTIONS

BW and SW contributed to the conception and outline of this review, and wrote the initial drafts of the manuscript. SS and TN contributed to the full draft and wrote sections of the manuscript specific to the training programs. All authors contributed to manuscript revision, and approved the final submitted version.

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# Making Family-Centered Care for Adults in the ICU a Reality

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Despite the value of family-centered care (FCC) in intensive care units (ICUs), this approach is rarely a reality in this context. This article aims to increase the likelihood that ICU-based care incorporates best practices for FCC. Consistent with this goal, this article begins by overviewing FCC and its merits and challenges in ICUs. It then offers a systemic framework for conceptualizing FCC in this challenging environment, as such a model can help guide the implementation of this invaluable approach. This systemic framework combined with previous guidelines for FCC in the ICU are used to inform the series of recommended best practices for FCC in the ICU that balance the needs and realities of patients, families, and the interprofessional healthcare team. These best practices reflect an integration of the existing literature and previously published guidelines as well as our experiences as healthcare providers, family members, and patients. We encourage healthcare leaders and interprofessional ICU healthcare teams to adopt these best practices and modify them for the specific healthcare needs of the patients they serve and their families.

**Keywords:** family-centered, families, patient-centered, intensive care unit (ICU), systemic

## MAKING FAMILY—CENTERED CARE FOR ADULTS IN THE ICU A REALITY

Patient-centered care (PCC) is a hallmark of quality care (1). This holistic model emphasizes an empathic, respectful relationship between the healthcare team and patient; ongoing bidirectional communication; and collaborative decision-making regarding care planning that is responsive to the preferences, traditions, and sociocultural backgrounds of patients and family members (2). Unfortunately, given the critically ill status of patients in the intensive care unit (ICU), these individuals often cannot communicate or participate in shared decision-making, the *sine qua non* of PCC. As a result, family members serve as surrogate decision-makers (3). Thus, this interprofessional authorship team that is comprised of physicians from multiple specialties (e.g., psychiatry, pulmonary and critical care, hematology), bedside ICU nurses, and family and clinical psychologists concur with other experts (4) that family-centered care (FCC) is essential and an ethical imperative (5, 6), in the ICU. However, we also recognize this rarely is the reality in this setting.

To help transform this reality, the goal of this paper is to provide healthcare leaders and interprofessional healthcare teams systemically-informed best practices for FCC in the ICU that aim to facilitate family presence, support family members, communicate optimally with families, seek helpful consultations, and optimize operations and the environment. These best practices are the outgrowth of an informal narrative review of the literature on FCC in general and its merits in the ICU, which are summarized briefly at the outset of the paper. They also capitalize on a systemic framework, which is subsequently overviewed. Further, they build upon existing guidelines on FCC in this unique context based on a systematic review (4, 7). Moreover, they reflect the clinical expertise of the interprofessional authorship team comprised of physicians (psychiatry, pulmonary and critical care medicine, hematology, and oncology), psychologists (couple and family, clinical, and clinical health), and bedside nurses. All of the authors are healthcare providers (HCPs) who provide FCC and some also receive ICU care as patients and/or family members.

This focus is relevant for frontline professionals in the ICU such as physicians, advanced practice providers, nurses, social workers, respiratory therapists, etc., who interact with patients and their families on an ongoing basis. It is often nurses and social workers based in the unit that serve many of the critical functions associated with FCC and who can lead the implementation of a FCC culture. It is also relevant to behavioral health professionals, including psychiatrists, psychologists, and advanced practice providers who frequently serve as consultants for ICU patients and often could be and are helpful in meeting the needs of these patients' families. In addition, although often not the case in ICUs with adults, ICUs that serve pediatric populations increasingly are incorporating behavioral health professionals on their integrated care teams in order to ensure that the psychological well-being of these youth and their families is a top priority (8). Ideally, moving forward, family-systems oriented behavioral health professionals can be added to ICU teams caring for adult patients to help ensure that the best biopsychosocial-cultural care is provided for these individuals and their families.

## FAMILY-CENTERED CARE

### Philosophy and Approach

FCC attends to the needs and values of each family unit (4). The patient or their surrogate decision-maker defines the "family," which may refer to life partners, close blood relatives (children, siblings), extended family, friends, and neighbors. "Family" refers to people who provide support and with whom the patient has a significant relationship.

FCC is guided by five principles (4).

- HCPs and the "family" discuss information and goals openly.
- All perspectives are welcome and cultural, spiritual, and religious beliefs and practices are respected.
- Collaborative decision-making about day-to-day care and life-sustaining treatment is prioritized; all parties have input.
- Negotiation about roles and decisions empowers "families" and capitalizes on their strengths, while ensuring all parties including HCPs are respected.
- With input from families, health systems create and implement family-centered and culturally responsive policies, practices, and systems. These principles focus primarily on the roles and responsibilities of HCPs. They do not guide family members in engaging effectively in this approach to care.

A component of patient- and family-centered care (PFCC), FCC improves patient, family, and HCPs' experience and satisfaction; reduces costs; and bolsters outcomes (7). FCC is associated with lower levels of stress and psychological distress among family members and better interactions with HCPs (9). When HCPs and families partner, FCC is beneficial for HCPs; it enhances their job performance, sense of efficacy, and well-being and lowers their levels of burnout (9). While there are similarities in FCC across all services within a healthcare system, the acuity and high levels of stress associated with the ICU for all parties require unique considerations when delivering this model of care in the ICU.

## FCC in the ICU Setting

### Benefits

FCC recognizes that family members are critical to their loved one's comfort in the ICU through offering love and companionship, helping with orientation, and responding to questions. Since ICU patients often are intubated or too ill to speak and family members are more knowledgeable about their loved one's wishes than the healthcare team, family members are essential for communicating the patient's thoughts and preferences to the team, advocating on behalf of the patient, and serving as surrogate decision-makers.

Despite the nascent empirical evidence for FCC in the ICU (3, 4), data indicate that FCC maximizes families' ability to be helpful care partners by ensuring they have ongoing contact with their loved one so they can provide them support, information, and meaningful communication (10). It helps families adapt to the ICU and associated unrelenting uncertainty (11) and enables them feel engaged as valued partners. Moreover, FCC fosters collaborative decision-making; it facilitates the family's capacity to make ethical and evidence-informed decisions and ameliorates some of the associated stress (3, 12).

Although interventions that target ICU patients' mental health do not positively impact family well-being (13), strategies relevant to families, such as communicating proactively, providing information, being inclusive, and offering emotional support ameliorate family members' stress levels, "family ICU syndrome," and "post-intensive care syndrome—family" (14, 15). "Family ICU syndrome" is characterized by physical morbidity secondary to sleep deprivation, psychological distress, cognitive difficulties, and interpersonal conflict (16) and "post-intensive care syndrome—family" refers to high levels of post-traumatic stress, anxiety, depression, and complicated grief reactions after a loved one is discharged from and/or dies in the ICU (17, 18). Further, FCC in the ICU increases families' well-being,

engagement, satisfaction, and self-efficacy, as well as decreases lengths of stay and costs (19, 20).

## Challenges

Yet, there are challenges to the practical implementation of FCC in the ICU. Even when healthcare teams value FCC, they often lack the necessary staff due to a combination of personnel, fiscal, and institutional commitment issues. They also may not have adequate time to invest in FCC; interacting with families and responding to their concerns is time intensive and can take time from other ICU responsibilities, including direct patient care. HCPs frequently express concerns about the time required for family-centered rounds or change of shift reports and the potential negative impact of such discussions on healthcare team members, learners, patients, and/or families.

Some HCPs experience stress when families are the bedside or want to interact with them (4), especially when families have unrealistic expectations about their loved one's care and prognosis or are dissatisfied with the treatment the patient or family receives (21). HCPs also struggle to balance caring for the seriously ill patient with attending to family members' concerns and emotional displays (e.g., yelling during a code while throwing self on the patient to preclude CPR, fainting and diverting attention from the patient) due to staffing limitations, insufficient training, and discomfort with the impact such displays have on patient care. The combination of multiple competing demands and staff shortages often leads to burnout (22), which negatively impacts the emotional well-being of both HCPs and family members. In addition, because of the high acuity, team turnover, and demands of the environment, interprofessional teams often find it difficult to communicate and collaborate (23), which negatively affects families. They also can have difficulties engaging family members in evidence- and value-informed decision-making due to the physical, psychological, and cognitive (e.g., difficulties synthesizing vast amounts of information) challenges of having a family member in the ICU; any history of personal or family conflicts; or previous experiences with healthcare systems (16). Additional, consultations often are not sought at all or in a timely fashion or are unavailable due to resource constraints (24).

Visitation policies, unit rules, limited staff resources, or staff members' attitudes and responses result in many families not feeling welcome (25) or that the care is attuned to their needs or their loved one's best interests (21). This often is the case when families do not experience the healthcare team's communications as transparent, frequent, or responsive to their questions and concerns (18). Communication problems may be most extreme with the when the patient is unable to give permission for the team share information (e.g., intubated, unconscious) and the team determines that sharing information is not in the patient's best interest, which is required by the Health Insurance Portability and Accountability Act (HIPAA). The interpretation of HIPAA is influenced by the extent to which the healthcare team practices FCC. Additional communication challenges that negative impact families relate to HCP's efforts to balance providing information and opportunities for engagement with protecting family members from distress and pain.

Operational and environmental factors serve as organizational barriers to FCC (21, 26). For example, families often are distressed about how the ICU environment itself, such as poor design (e.g., multi-bedded rooms, open ICUs, and insufficient space for family), limited privacy, high noise levels, and lack of resources (e.g., inadequate waiting rooms, limited access to food, and drink) interfere with care that is family-centered (21, 25).

Finally, the COVID-19 pandemic and its associated limitations on visitation made the provision of FCC more challenging and demanding, although it also brought to light how valuable it was for all parties concerned for families to be present or at least engaged in meaningful ways. Moving forward, family members are likely to expect ICU teams to continue to incorporate creative ways to engage loved ones unable to be present as they did throughout the pandemic (5).

## SYSTEMIC FRAMEWORK TO GUIDE FCC IN THE ICU SETTING

Despite the advantages of FCC in the ICU setting and guidelines for its implementation (4, 7), such care is often not a reality. While the aforementioned challenges offer a partial explanation, they do not tell the whole story. Many of these challenges can be moderated by the leadership, infrastructure, processes, and procedures associated with systems-based care.

Systems thinking offers a helpful framework for conceptualizing the multilayered aspects of ICU patients' medical situation, from the biological processes that account for their health status, to the psychological processes that influence their coping and adaption, to the family/social, and cultural contexts in which they are embedded (27, 28). It lays the foundation for viewing families as essential to patients' health and well-being, allies in care, and key members of the care continuum and caregiving team. Systems thinking leads to an understanding of ICU systems as holistic, dynamic, complex, and characterized by reciprocal interrelationships within the system and between subsystems (29, 30).

At a systems level, FCC is most successful in healthcare organizations that prioritize systems thinking and systems-based practice, a core competency in medicine (31). For FCC to become the norm, it must be embraced by organizational leaders and those at the helm of the ICUs. These leaders must emphasize combining quality clinical medicine and physical care; having informative and compassionate interactions with families; creating an inviting and culturally responsive environment; and ensuring that the healthcare team is adequately staffed, resourced, trained, and supported in providing FCC.

For FCC to be truly integrated and advanced within ICUs more universally, healthcare leaders, and professionals must be well-informed about and appreciate the value of a systemic framework. ICU teams that embrace a systemic approach create a culture that emphasizes systemically-informed understandings of patients, families, teams, and health systems and incorporates associated best practices (29). With the support of healthcare leaders, these teams integrate FCC into the infrastructure of the unit such as through the mission and vision,



policies and procedures, approach to care, job descriptions, performance evaluations, unit design, documentation, and quality improvement activities (23, 32–34). Unfortunately, many healthcare organization leaders and HCPs fail to adopt a systems approach to thinking, despite how crucial it is to effective system-level redesign. As a result, healthcare systems and leaders often do not buy-into FCC; they fail to support or reinforce HCPs and ICU teams in achieving its aims even though doing so typically is a win-win-win situation (21).

Embracing a systemic approach requires training HCPs to think systemically and appreciate the benefits of FCC based on empirical data and hands-on experience. HCPs are more likely to engage in this approach to care if they receive role modeling, training, and guidance to carry out FCC in the ICU along with the message that this model is valued within the organization and the ICU (21, 22). Ongoing training should inculcate in ICU team members a value on viewing families as care team members and partners who can be a resource and support, rather than as visitors or intruders who cause them undue burden. To assist them in carrying out this value, such training must be designed to teach HCPs how to individualize care to each family, integrate family members as desired in the patient's care, and harness the family's strengths in support of the patient's care. This training should also teach HCPs the skills necessary for incorporating family members' expertise in patient and family values and needs into the biopsychosocial-cultural care that is provided (5). It must help them become more facile at making decisions that include multiple points of view in a manner that attends to the nested and interacting levels of the healthcare system (e.g., patient, family, team, ICU, hospital, political, and economic context).

ICUs that adopt a systemic framework also must invest in making unit-based changes to improve care delivery to patients and families. One beneficial change for units to consider is adding a family navigator and/or family support specialist to the interprofessional care team who can serve as a bridge between the healthcare team and the family. Such an individual may be a family-systems trained behavioral health professional such as family psychologist, psychiatrist, medical family therapist, or advanced practice professional. This individual may assume primary responsibility for educating each family about FCC in the ICU. This involves conveying that FCC is a dynamic relationship between families and the team, gathering information about family members' expectations, and providing information about reasonable expectations for FCC and the patient's likely course. It also involves offering tools for the family to participate in FCC (e.g., teach them about procedures and basic care) and acknowledging and normalizing the family's understandable range of emotions (e.g., shock, fear, and anger) and trauma. Moreover, this individual can serve as a critical function in providing family members with practical and emotional support and fostering discourse between the healthcare team and the family. This team member should be empowered to facilitate and mediate team-patient-family communication, support shared decision-making, help the family navigate differences, and attend to the emotional well-being of all parties (34, 35). There is evidence incorporating a systems-thinker and practitioner on the team improves

satisfaction with care for HCPs and families alike (35). When such a designated professional is not available, the functions they serve must be assumed by other team members.

Another approach to improving FCC is to create and utilize an advisory group comprised of prior ICU patients and family members (36). Ideally, their input is sought on ways to make ICU operations and environment more patient- and family-centered. They also can be engaged in problem-solving solutions for navigating the challenges of balancing staff responsibilities and demands with the needs of patients and their families.

## BEST PRACTICES FOR FCC IN THE ICU

The five best practices build upon evidence-informed guidelines for FCC in ICUs with adult patients (4, 7). They expand upon these guidelines in three ways. First, they are guided by a systemic framework. Second, they incorporate recent evidence and the collective wisdom and clinical experience of the interprofessional authorship team. Third, the best practices are delineated in a comprehensive fashion and include specific implementation strategies. We believe that ICUs that employ these best practices will more effectively engage and support family members as respected collaborators in care, foster families' understanding of the situation and their new roles, improve healthcare team-family communication, and enhance family participation in decision-making (37). While no ICU can incorporate all practices and must decide which to prioritize in their policies, procedures, and processes based on their setting and values (3), systemically informed FCC must be a core value.

### Encourage and Facilitate Family Presence

Families play critical roles in caring for their loved ones in the ICU; they partner with HCPs in providing care, aid in decision-making, and improve safety and quality. Twenty-four hour visitation and ongoing access to information and opportunities for hands-on-care and support are associated with positive family outcomes and satisfaction (38). Thus, as detailed in previous guidelines, policies related to family presence should be open, flexible, and unlimited (4, 7) and optimally include open-door visitation (22, 38, 39), with restrictions only when necessary. Visitor policies need to be followed consistently and not used to control the unit and/or particular families or family members.

Such policies are best implemented if HCPs are informed about the benefits of enhanced visitation and embedded in a unit culture that values families' preferences about their presence and their engagement. This can be accomplished by HCPs educating families about how being at the bedside may support or stress the patient and ways to respond accordingly. It requires healthcare team—family collaboration in determining when the family should be present (e.g., patient becomes calmer or better oriented, family feels too stressed when not present) and when to leave (e.g., increased agitation in patient, family member needs sleep). HCPs should promote helpful contact by guiding family members in caring for and supporting the patient (e.g., feeding, facilitating range of motion exercises, bathing, and reading to them) or personalizing the patient's room so it is familiar and conveys who they are as a person (39). HCPs must learn from

the family about the patient's likes/dislikes to inform future interactions (40).

Prior guidelines recommend offering family members the option to witness procedures or medical interventions (e.g., cardiopulmonary resuscitation) (CPR) (4, 7) given evidence that many relatives desire to be present and find such presence beneficial and that family presence does not disrupt patient care (41). Families who opt to be present should be provided with support and guidance from a designated staff member so they are not unduly traumatized (22, 41). The same should occur if family members are not physically present but desire such information.

Encouraging presence also means including family in staff communications about the patient (4). Families appreciate such inclusion and it positively impacts the patient and family experience (42). Families can be included if nursing change of shift reports and interprofessional rounds occur at bedside and are family-centered. Family members should be informed about the timing and purpose of these activities, appropriate times to ask questions (e.g., during and/or outside of rounds) and realistic to expect responses and updates, and the reason these activities cannot be at bedside (e.g., patient in isolation limiting number of people in the room). HCPs are most open to bedside processes if they know they reduce errors in information transfer, foster collaboration and dialogue, and increase family satisfaction (42, 43).

It is important for interprofessional [e.g., ICU physician(s), nurses, social workers, behavioral health professional(s), family navigator or support person, other team members] family-oriented care conferences to be held (15, 22). Ideally, these conferences cover introductions, goals of the conference, patient's medical situation and prognosis, and potential future decisions and outcomes. Often these conferences need to involve end of life conversations that attend to the family's definition of quality of life, patient's view if possible, and patient and family values. The family should be invited to ask questions that are responded to and their feelings and perspectives should be acknowledged. Family members should be engaged in shared decision-making including about complex issues. These conferences should conclude with a summary of goals, decisions, and next steps.

When family members are unable to be physically present, the healthcare team should engage them virtually (daily if possible) so they can offer their loved one support and comfort. This can be facilitated by having a telephone in every room, making I pads available, and/or using the patient's personal device. Units need to incorporate technology (e.g., smartphone apps, social media) that enable family members to carry out critical functions for the patient, regardless of whether they are at the bedside. While the COVID-19 pandemic has made FCC in the ICU more challenging, it has advanced our capacity to communicate effectively with families *via* technology when they are unable to be at the bedside. These advancements must continue to be integrated into ICU care in the future.

## Support Each Family and Its Members

Existing guidelines emphasize supporting families (4, 7) so they feel less overwhelmed, distressed, and traumatized (18). This involves prioritizing friendly and compassionate interactions

with family members (16). Examples include HCPs introducing themselves and their role on the team to the family repeatedly, orienting families to the setting, being mindful not to ask questions that are perceived as repetitive and/or unnecessary, and explaining their actions as they perform them. All such interactions must reflect empathy and kindness as well as competence.

In accord with medical family therapy, which builds upon a systemic framework, supportive interventions should aim to bolster family members' agency and personal choice, foster their interpersonal connections, and promote family functioning and well-being (44, 45). This entails attending to family members' psychological reactions, needs, and wishes; identifying their strengths; helping them manage their lives and stress; encouraging them to prioritize self-care and accessing resources; and providing them necessary resources (e.g., lip balm, exercise room in the hospital, library services, and internet access).

Prior guidelines recommended specific mechanisms for supporting families. The first is education, which involves providing basic information that fosters family members' comfort in the ICU. It entails conducting a family meeting that focuses on information about the ICU, ICU rules and their rationale, machines in the patient's room, realistic expectations, and roles they may play (e.g., companion, assistant, representative, and planner). During these discussions, families should be prepared for potential setbacks and negative outcomes while also being given appropriate hope. While optimally such a meeting and associated support is provided from the outset of the admission (i.e., within the first 24–36 h), family members may not be present or reachable initially, and thus may need to occur at a later time. Unfortunately, a standard orientation process can be challenging because of variability in families' expectations about ICU care, their stress levels, and their capacity to cope. But it must be standard practice to transmit relevant education and information to family members in a timely fashion. Families also can benefit from receiving written materials (e.g., brochures, booklets) and/or having videos that review the aforementioned information and address pertinent topics (e.g., death and dying, grief).

A second mechanism is ICU diaries, which are documents crafted daily by family and/or staff (19, 46). Both family members and HCPs should be encouraged to chronicle the events leading to an ICU admission or intubation and subsequent progress or setbacks and express related emotions. HCPs should commit to family that if they leave the bedside, a HCP will document in the diary and contact the designated family member if there is a noteworthy change. These ICU diaries should be shared with the patient during their recovery or upon discharge so they learn what they experienced or with the family if their loved one dies to assist them with debriefing or reminiscing.

## Prioritize Communication With Families

Existing guidelines highlight the value of ICU team—family communication that is respectful, emotionally attuned, empathic, supportive, and patient-focused as well as family-centered (4, 7). For this to be realized, it often requires creating a plan in which a point person for the healthcare team is assigned (individual

or role) to communicate regularly with the designated family member(s) and this person's word should be considered official when there are mixed messages. The family needs to be informed how to contact this individual if they have questions or concerns and if they are unavailable, who they should reach out to and how. Similarly, there needs to be a clear understanding among all parties about the family member who will serve as the liaison for information, questions, and concerns between the healthcare team and the family. If the patient has designated a decision-maker, this person is easily identified. If not, the healthcare team should ask the family to designate one or two point people. In accord with the growing OpenNotes movement, these designated family members may meet the requirements for being proxies (i.e., care partners) who can access the patient's electronic health record and review medical information in that way.

Intentional family-centered communication involves healthcare team members sharing information regularly (i.e., at minimum daily) and in an honest, transparent, timely, and proactive manner; ensuring it is understandable and realistic; and not glossing over bad news (25, 39). When possible, they can provide information visually (e.g., radiographic imaging). HCPs need to repeat critical information as often as necessary and with patience. Further, it helps if they acknowledge the challenges providing FCC and ask each family for guidance on doing so optimally for them. HCPs must do their best to mitigate problematic interactions through discussion and shared problem-solving, rather than avoidance or hostile communications.

Family-centered communication requires HCPs to listen actively to family members; attend to their values, feelings, concerns, questions, and goals; and mobilize their resilience and enhance their psychological well-being as they function as care team members and surrogate decision-makers (44). A structured approach to such communication often is valuable. One helpful mnemonic is "VALUE" (47):

- V = value family statements,
- A = acknowledge family emotions,
- L = listen actively to the family,
- U = understand the patient as a person, and
- E = elicit family questions.

The use of a structured communication tool results in greater satisfaction and more realistic expectations about survival (48).

Related to ensuring effective communication, prior guidelines also emphasize shared decision-making, which enhances family satisfaction with care and clinicians' sense of efficacy (4, 7). The following are specific strategies for engaging families in shared decision-making (12, 16, 49–51). First, HCPs need to solicit family members' wishes about their preferred level of involvement and gather information about the family's goals of care and perceptions of the patient's priorities related to treatment planning. They then need to identify clear decision points, provide pertinent information about the patient's current clinical situation and potential options, elicit family members' perspectives and help them navigate differences in these points of view, guide the family toward a final decision that hopefully has buy-in from all parties, and assess the family's comfort with

the decision(s). This process, which can be repeated whenever there is a decision to be made, can be facilitated by decision aids. Collaborative decision-making in which the family is empowered to serve as a true partner with the healthcare team takes time; involves a focus on medical and nonmedical goals; and requires HCPs to listen to, respect, and accept the input (49, 50). The process of collaborative decision-making should be documented in the electronic health record (52).

Critical to effective communication is HCPs overcoming their reluctance to having difficult conversations, such as about end-of-life (49). When such conversations are held, team members known well to the patient or family should be present. The discussions should occur early and often enough in the trajectory of care that patient and family input truly matters (40, 49).

## Seek Consultation

An additional guideline pertains to accessing one or more consultation services in support of FCC (4). Such consultations often reduce family members' levels of psychological distress and increase their satisfaction with care, increase the attainment of clinical consensus, and shorten patients' lengths of stay (18, 43). Seeking appropriate consultations aligns with a systemic framework's emphasis on interrelations between systems, such as units within the healthcare system.

The following are three examples of systemically-informed consultations. For many patients in the ICU, palliative care consultations should be episodic or ongoing (53). These consultations, which should occur in collaboration with the ICU team as discussed above, typically need to focus on goals of care and end-of-life decision making. Palliative care consultants often can assist ICU teams in communicating the prognosis of seriously or terminally ill adults to families and patients, respecting family members' needs and autonomy (if patient is not competent to make decisions) about life sustaining treatment vs. end of life care, and attending to differences within families when these emerge. These consultants often are excellent models for ways ICU teams can be attuned to and respectful of family members' cultural, religious, and spiritual beliefs related to end-of-life care, as well as their associated emotional and spiritual needs. As a second example, ethics consultations can support patients, families, and the team in ethically challenging situations (54). Such consultations can be useful for clarifying goals of care and addressing disagreements between the ICU team and surrogate decision-makers. A third example is consulting with spiritual support/pastoral care if consistent with the family's wishes (53). Members of the spiritual support/pastoral care team can serve an invaluable function in listening to family members' emotional pain, supporting them in grappling with existential questions, offering compassion, and providing spiritual/religious support. The inclusion of a chaplain in ethics discussions can assist family members in determining the extent to which decisions are consistent with patient/family beliefs and providing them support for the decisions made. It behooves HCPs to recognize the critical role chaplains play in advocating on behalf of patients and families and serving as ambassadors between the healthcare team and the patient-family system.

## Optimize Operations and the Environment

Previously detailed guidelines related to optimizing operations and the environment (4, 7) are in keeping with a broad conceptualization of systems that recognizes that human behavior occurs within a contextual matrix of individual, interpersonal, environmental, or macrosystemic factors (30, 55). These environmental and macrosystemic factors must be considered to ensure FCC. In other words, hospitals need policies, procedures, and processes that promote FCC in the ICU in concrete ways. In keeping with the movement toward humanizing care within ICUs, these policies, procedures, and processes need to support open visitation and family engagement, foster positive communication (e.g., among HCPs; team-patient-family), incorporate mechanisms to trigger early conversations about goals of care, and ensure humane operations and environment (39). They need to lay the foundation for HCPs to be intentional about supporting families and communicating with them effectively, mitigate against and ameliorate family ICU syndrome and post-intensive care syndrome—family, and prioritize compassionate end-of-life care. In a related vein, healthcare organizations need to create systems that support FCC (49). Examples of this include making available relevant technological supports and developing a section of the electronic health record in which HCPs record information shared with the family, goals of care conversations, family input in and conflicts about decisions. Such systems need to embrace quality improvement efforts designed to monitor and assess indicators of FCC, evaluate family satisfaction with ICU care, and examine HCP's perceptions of support and necessary resources for such care. Moreover, healthcare systems overall and ICUs specifically must hire and retain staff that prioritize FCC and train staff to be competent in this approach. Staffing models need to be refined and optimized to include people with expertise in FCC who can meet the unpredictable workloads and demands of FCC.

Units must strive to create a welcoming environment in which family members feel respected as valued members of the care team (25, 39). The physical nature of these environments should be family-friendly, with adequate places to sit, sleep, and take a break. HCPs should facilitate nighttime rest by minimizing noise levels and lights and ensure families have access to nourishment when desired. Healthcare systems need to devote resources for family self-care (e.g., bathrooms and showers, kitchens, and laundry rooms) and make accessible spaces where family members can find serenity (e.g., gardens, Zen rooms).

Finally, ICUs must care for their HCPs (39) by creating organizational conditions and environments that support interprofessional teamwork, emphasize competency attainment associated with teamwork (e.g., coordination, communication, and adaptability) and interprofessional collaboration, and promote mechanisms for accurate transfer of patient information among team members. Interprofessional teamwork improves patient outcomes, team functioning, patient and family satisfaction, and provider well-being (23, 56, 57). ICUs that care about their HCPs prevent and address burnout through educating people about this syndrome, encouraging the use

of strategies to bolster their resilience, and transform the organizational culture from one that engenders burnout to one that supports HCPs well-being.

## CONCLUDING COMMENTS

Moving forward, for FCC to become the *sine quo non* of quality care, studies on its implementation, added benefits, and outcomes in the ICU are critical. Such investigations may examine key elements of FCC in this setting, ways to tailor care to each family and unit, and strategies for incorporating FCC into daily practices. They may focus on developing, executing, and evaluating new approaches to improve families' well-being and quality of life and innovative programs to guide families in participating in FCC (58). The benefits of a systemically informed behavioral health professional on the team for patient, family, and staff well-being and outcomes should be examined. Studies must address ethical challenges, such as family engagement in care planning and delivery in light of legislation (e.g., HIPAA) (59). Such research will be most valuable if family members and former patients are partners on research teams and inform the questions being addressed, the constructs assessed, and the interpretation of the findings.

There are genuine challenges to implementing FCC in ICUs that serve adults. Embracing this model of care requires healthcare systems and ICU teams to make tradeoffs, some of which are quite challenging. It is possible that some of these compromises could lead to negative consequences and even harm. Thus, quality improvement initiatives must ascertain the advantages and disadvantages of shifting an ICU culture toward one that is family-centered; guide efforts to mitigate negative outcomes; and inform decision-making when the selection of FCC processes or procedures has a problematic impact on patients, families, and/or units.

Further development, implementation, modification, and dissemination of FCC programs in ICUs with adult patients requires input from all parties. This will help ensure that care both responds to the preferences, needs, and values of patients and families and respects the practical and emotional demands such care places on HCPs.

In closing, despite its challenges, FCC in the ICU promotes the health and well-being of patients, family members, and HCPs. By working as partners, all parties are empowered to collaborate as allies in the patient's healthcare journey.

## AUTHOR CONTRIBUTIONS

AS and NK assumed primary responsibility for writing the manuscript, although all other authors participated actively in editing the manuscript. SD offered expertise as a patient, as well as a patient- and family-centered care psychologist. HS offered her views based on providing family-centered psychological services in the ICU. AV provided expertise as an ICU physician and leader. DG offered expertise as an ICU nurse. DT provided expertise as a specialist who consults frequently



in the ICU. All authors participated in the conceptualization of the manuscript and the determination of the recommendations.

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# A Multidisciplinary, Family-Oriented Approach to Caring for Parents After Miscarriage: The Integrated Behavioral Health Model of Care

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Miscarriage is increasingly gaining recognition, both in scientific literature and media outlets, as a loss that has significant and lasting effects on parents, though often disenfranchised and overlooked by both personal support networks and healthcare providers. For both men and women, miscarriage can usher in intense grief, despair, and difficulty coping, and for women in particular, there is evidence of increased prevalence of depression, anxiety, and post-traumatic stress. Additionally, miscarriage can contribute to decreased relationship satisfaction and increased risk of separation, all while stigma and disenfranchisement create a sense of isolation. Despite this increased need for support, research indicates that many parents experience their healthcare providers as dismissive of the significance of the loss and as primarily focusing only on the physical elements of care. Research exploring the barriers to providers engaging in more biopsychosocial-oriented care has identified time constraints, lack of resources, lack of training in addressing loss, and compassion fatigue as key areas for intervention. This paper will review the biopsychosocial elements of miscarriage and discuss a multidisciplinary, family-oriented approach that can be implemented in healthcare settings to ensure a high quality and holistic level of care for individuals, couples, and families experiencing pregnancy loss.

**Keywords:** miscarriage, pregnancy loss, perinatal loss, biopsychosocial, integrated care, family-oriented approach, multidisciplinary approach, primary care behavioral health integration

## INTRODUCTION

Miscarriage is a medical event with a complex combination of psychosocial sequelae, however research indicates that healthcare providers and clinical teams often fail to attend to the complex and sensitive nature of miscarriage (1, 2). For many parents, miscarriage is a traumatic loss, but not always recognized as such by important sources of support in their social and healthcare networks (1–4). This paper will review the biopsychosocial elements of miscarriage, discuss barriers to biopsychosocial approaches to miscarriage care, and propose a family-oriented, multidisciplinary approach that can address these barriers and provide parents with holistic, sensitive care after their loss.

## A BIOPSYCHOSOCIAL UNDERSTANDING OF MISCARRIAGE

### Biological

Miscarriage is more common than people often believe (5), occurring in about 31% of all pregnancies, though a portion of these occur prior to a woman's knowledge of her pregnancy (6, 7). In clinically diagnosed pregnancies, about 8–15% end in miscarriage (8, 9). Miscarriage, early pregnancy loss, and spontaneous abortion are all terms that are used interchangeably to describe the loss of a pregnancy during the first 20 weeks (10). Miscarriage and the resulting experience of loss are distinct from other perinatal losses, such as stillbirth, which is the death of a fetus after 20 weeks' gestation, or elective abortions that surgically or medically end a pregnancy prior to fetal viability (11).

There are several risk factors associated with miscarriage, including advanced maternal age, certain medications, maternal infections, and previous miscarriage (9). However, the majority of miscarriages do not have a known cause, and this can create additional challenges as parents attempt to understand what has happened, cope with the loss, and plan for future pregnancies (12). A large number of myths exist regarding other contributing factors for miscarriage (e.g., air travel, sexual activity, a prior elective abortion), though these have garnered no scientific evidence of increased risk of miscarriage (9, 13). Once a miscarriage has occurred, some biological factors are also associated with worse psychological outcomes, including older maternal age (14), history of infertility (15), unknown cause of the pregnancy loss (16), and recurrent miscarriages (17).

Previously, most miscarriages were managed in the hospital setting, and though these patients continue to be cared for in emergency departments and on labor and delivery floors, present-day miscarriage management now occurs more frequently in the outpatient setting with a patient's primary care physician or OB/GYN (9). There are three management strategies: (1) expectant management, in which the body manages the loss on its own, (2) medical management, in which the patient is sent home with medications to aid the miscarriage process, and (3) surgical management, in which the miscarried pregnancy is surgically removed. Choosing between these management options can be a difficult decision for patients, and provision of information, opportunity to ask questions, and assurance that this choice will not affect future fertility are important elements of care for these patients (9, 18, 19).

### Psychosocial

Though often perceived as a loss primarily impacting women (and for lesbian partners, the partner who carried the pregnancy), miscarriage impacts both partners in a relationship (20–22), and even other family members, as well (23). For both men and women, miscarriage can usher in intense grief, despair, and difficulty coping (24), and for women in particular, there is evidence of increased prevalence of depression, anxiety, and post-traumatic stress (25, 26). Positive social support, a satisfying partner relationship, and already having a child are protective factors against depression and anxiety after this loss (27).

Though grief has been shown to decrease over a 4 month period for both genders, isolation, feelings of loss, and the perception of the loss as a devastating event can persist over time (24). Many women may also place blame on themselves for the loss, experiencing significant guilt and feelings of failure as a woman or as a mother (28). Grandparents of the baby may experience grief as well, and the experience of seeing their own child grieve can add complexity to that loss (29). Siblings are an additional group that may struggle, sometimes invisibly, with miscarriage; as parents attempt to cope, siblings' questions and feelings of loss may inadvertently be overlooked (30). Each of these grief experiences can be exacerbated by the disenfranchisement of this loss.

Disenfranchisement is a key element in a biopsychosocial understanding of miscarriage. A disenfranchised loss is a loss that is "not openly acknowledged, publicly mourned, or socially supported" [(31), p. 4]. A growing body of research points to disenfranchisement as an aspect of miscarriage that impedes parents' abilities to successfully grieve and cope with their loss (2–4, 32). Though social support is a critical factor in bereavement outcomes (33), family members, friends, healthcare providers, and even society more generally often fail to understand and validate the meaning and significance of miscarriage loss. The lack of understanding about grief after miscarriage is pervasive, and likely perpetuated by the norms of silence surrounding early pregnancy and pregnancy loss (34).

Though often well-intentioned, many family members and friends make statements that minimize the loss (e.g., "You can always have another," "At least you know you can get pregnant"), resulting in bereaved parents feeling they do not have permission or space to experience and express their grief (2). Medical providers across multiple specialties (particularly OB/GYN, primary care, and emergency) regularly care for parents experiencing miscarriage, however, research indicates that bereaved parents are infrequently asked how they are coping after a miscarriage and often experience their providers as dismissive of the loss, which has been shown to increase women's distress (1, 4).

In addition to impacts on individual partners, research shows that miscarriage can also significantly impact the couple relationship. During a time when stigma and disenfranchisement can create a sense of isolation for one or both partners (3), miscarriage is also associated with decreased relationship satisfaction (35, 36) and increased risk of separation (37), further compounding the stress and difficulty coping parents may experience after their loss. Research indicates that these relational impacts result from high levels of distress (38), differing perceptions of the meaning of the loss (4), incongruences in expression of grief and desired support (36, 37), avoidance coping strategies that reduce emotional support within the relationship (35), and even different expectations between partners regarding how to react to the loss and how to grieve (4, 35). However, despite these challenges, some couples experience relationship growth after miscarriage as a result of turning toward each other for support during a difficult time, embracing both similarities and differences in their grief, and experiencing support and care from their partner (39, 40). Partners experiencing growth



after miscarriage cite availability of and quality of support as important factors enabling this growth (39). Enhancing support across both personal and healthcare networks may improve parents' abilities to cope with this difficult loss, and perhaps even contribute to reductions in the level of disenfranchisement accompanying miscarriage.

## CURRENT CHALLENGES IN MISCARRIAGE CARE

Healthcare providers are frequently a patient's first point of contact during or after miscarriage as they experience concerning symptoms, seek help, and receive a diagnosis, or as they follow up with their provider and discover their baby is no longer growing as expected. As this first point of contact, healthcare providers are a crucial first step in supporting parents as they navigate this loss. However, research has consistently documented significant gaps in the psychosocial elements of miscarriage care, including lack of empathy, treating miscarriage as routine and trivial, failing to attend to grief and loss, and lack of clarity in communication about the miscarriage and next steps (1, 4, 41–44).

A recent study by Jensen et al. (45) investigated healthcare providers' experiences, and found that these limitations in care are largely due to a lack of training in managing the psychosocial aspects of miscarriage, limited time, inadequate resources, and compassion fatigue. Additionally, many medical schools and residency programs lack a strong emphasis even in the medical management of miscarriage, beyond expectant management (46–48), which may reduce healthcare providers' abilities to engage patients in shared decision-making regarding miscarriage management, an important element of care associated with patient satisfaction (49). Though many healthcare providers would like to provide biopsychosocial-oriented care, they simply lack key resources to do so.

## A FAMILY-ORIENTED, MULTIDISCIPLINARY APPROACH TO MISCARRIAGE CARE

In light of the overwhelming amount of evidence indicating the sub-par quality of existing approaches to miscarriage care, researchers are calling for new methods of care and new interdisciplinary team members to improve care across all levels of the biopsychosocial spectrum (42, 50). Current recommendations for enhancing psychosocially-oriented, patient-centered care include: (1) attending to the emotional significance of the loss, (2) providing more information to parents regarding miscarriage management and impact on fertility, (3) engaging patients and their partners in shared decision-making, (4) implementing screening to identify needs for additional mental health support and (5) developing a referral system and resource list to connect parents with this support (1, 50–53). DiMarco et al. (54) have also recommended the implementation of educational programs to build healthcare providers' expertise in delivering this kind of supportive miscarriage care. To address these recommendations, we suggest

three key strategies for implementation of a family-oriented biopsychosocial approach to miscarriage care that can facilitate these important action items while simultaneously addressing the barriers that impede their use (e.g., time constraints, lack of resources, compassion fatigue).

### Establish a Multidisciplinary Team

The integrated behavioral health (IBH) model of clinical practice is an innovative and multidisciplinary approach to care that can address the barriers to high quality miscarriage care and enable healthcare practices to implement these care recommendations. In the IBH model, behavioral health providers (BHPs) are hired by the clinic, creating a multidisciplinary team able to address both biological and psychosocial elements of miscarriage under one roof (55). These clinicians come from a variety of professional backgrounds, including marriage and family therapy, professional counseling, clinical social work, and psychology. The care team members in these integrated clinics work side by side and within the same electronic health system to enable collaborative, team-based care (56).

To adapt to the healthcare setting, BHPs in these practices conduct appointments that range from 15 to 30 minutes, while also maintaining flexibility in order to be available for consultations with physician and nurse team members (55). During these consultations, the care team may decide to coordinate a "warm handoff" to connect a patient to a BHP. In a warm handoff, a physician introduces the patient to the BHP during the patient's medical visit, creating space for the BHP to establish rapport, as well as conduct a brief intervention and/or discuss treatment options (57). Though most frequently implemented in primary care, this model can also be adapted for other specialties that regularly care for patients experiencing miscarriage, such as emergency departments and outpatient OB/GYN clinics (58, 59).

### Develop a Miscarriage Protocol

Through this collaborative approach, the care team shares responsibility for each patient's well-being. Clinical settings using this model of practice often develop clinical protocols for specific diagnoses or conditions for which a BHP is regularly involved (55). In these types of protocols, the clinic's BHP is automatically connected with patients who meet specific criteria (e.g., diabetes diagnosis, positive depression screening, smoking cessation counseling). Miscarriage can be included in these protocols, establishing a behavioral health warm handoff as a regular part of miscarriage care in that clinic. This warm handoff can include an assessment of how the patient and their family are coping, create space for empathy and validation of the loss, offer psychoeducation regarding grief after miscarriage, and discuss what support and resources are available to them.

During the initial assessment, the BHP works collaboratively with the patient and family to discuss support needs and follow up options. Subsequent to the initial warm handoff, the BHP schedules follow up appointments based on each patient and family's treatment needs. For some patients, helpful follow up options may also include connection to pregnancy loss support groups, pastoral or spiritual support, and additional fertility

information from their medical provider (e.g., fertility treatment options, genetic counseling). In the IBH model, BHPs and medical providers work collaboratively in the treatment of each patient, communicating about clinical assessments, treatment goals, and progress.

By implementing a multidisciplinary care team and standard involvement of a BHP for all patients experiencing miscarriage, healthcare teams can improve the quality of care patients receive by increasing access to psychosocial care and reducing the amount of care burden that falls to physician team members. Though not all patients will require the same level of support, all patients will know this support is accessible to them if needed. When physicians are no longer tasked with the impossible job of caring for all elements of a patient's health in a small window of time, they may experience reduced stress levels and feel more freedom to engage with the psychosocial elements of miscarriage care knowing they have a team member with whom they can connect their patient (60). This shared-care protocol may also create more space for shared decision-making regarding the medical management of miscarriage, as well as more time for physicians to address patients' concerns about future fertility.

## Consider Family

Because miscarriage is often viewed primarily as an issue affecting mothers, other family members struggling with the loss may be overlooked. A growing literature base is identifying fathers' needs for support after miscarriage (61), and grandparents and siblings of the baby may also benefit from support as they navigate what the loss means for them (62, 63). With this type of loss often unacknowledged or misunderstood for mothers, other family members' grief may be even more invisible. Additionally, miscarriage can create stress in partner and family relationships as individuals cope in different ways and struggle to navigate the loss together (35, 39).

Miscarriage's broad impact on multiple family members, as well as on the relationships between partners and family members, highlights the need for care that is not only biopsychosocial, but also family-oriented. Clinicians working with women experiencing miscarriage can expand their assessment to include questions about the patient's support system and how those individuals are responding to the loss. This practice can increase the amount of support a family receives through opportunity to connect family members to behavioral health services, as well as offer other miscarriage support resources. BHPs can invite partners and family members to participate in the behavioral health services they provide their patients. This couple and family level of care can support family members in exploring their unique experiences of the

loss, meanings of the loss, issues related to identity and guilt, expression of grief, grieving together and separately, emotional intimacy after loss, physical intimacy after loss, and shared experiences of disenfranchisement (3, 28, 36, 39). Additionally, for primary care practices, the patient may be a partner or family member of someone who has miscarried; as part of a biopsychosocial approach applied to all patients, providers may discover the impact of miscarriage while treating these patients and have an opportunity to mobilize the clinic's additional resources for them as well.

## CONCLUSION

Though there is extensive research on psychological outcomes after miscarriage, primarily for women, there remain significant gaps in the literature base regarding a family-oriented understanding of the experience of miscarriage, family level grief outcomes and relational impacts, and biopsychosocial-oriented healthcare for patients and families facing this loss. Additionally, research has not yet tested the IBH model in miscarriage care. As an existing, evidence-based model of care (64, 65), IBH represents an important opportunity to address the limitations of current miscarriage care, as well as the barriers to implementation of family-oriented, biopsychosocial care (1, 41, 44).

As many patients' first point of care for miscarriage, healthcare providers are in a unique position to positively influence these patients' loss experiences. Empathic, biopsychosocial care can set a trajectory for successful coping and sufficient support, particularly during an experience that is often disenfranchised. By implementing an integrated behavioral health model of care, creating a protocol, and considering patients' larger familial context, healthcare providers can increase the amount of support and resources available to bereaved parents and their families.

## DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

## AUTHOR CONTRIBUTIONS

AH led the conception and outline of this manuscript. AH and AV contributed as co-authors to the full draft of the manuscript. All authors contributed to the article and approved the submitted version.

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# A Biopsychosocial-Ecological Framework for Family-Framed Dementia Care

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The biopsychosocial model has been applied through collaborative care dementia models to the diagnosis, symptom management, and treatment of dementia with a focus specifically on the person with dementia. Because individuals with dementia are increasingly dependent upon others particularly as the illness advances, dementia care requires the involvement and commitment of others, usually family, along with support from community-based resources. Hence, the quality and effectiveness of a person's dementia care are shaped in large part by the foundation of family relationships and the social and community networks in which they are embedded. While most current dementia care models incorporate biopsychosocial principles and recognize the essential role that family members play as caregivers, they fail to consider a patient's family system and relationships as potential risk factors or social determinants for care outcomes. This paper introduces a biopsychosocial-ecological framework to dementia care that is person-centered and "family-framed" in that it targets factors that influence care considerations at both the individual and relational levels of the social ecological networks that the patient and their family members occupy. We use this model to illustrate how current dementia care practices tend to focus exclusively on the individual patient and caregiver levels but fail to identify and address important relational considerations that cut across levels. We call for the need to add assessment of family relational histories of persons with dementia and family members who care for them in order to better meet the needs of the patient and the caregiver and to prevent harm. This model accentuates the need for interprofessional education on family assessments and caregiver-centered care, as well as interdisciplinary, collaborative models of dementia care that assume more accountability for meeting the needs of family caregivers in addition to those of persons with dementia.

**Keywords:** person-centered care, biopsychosocial, social ecological, family relations, family systems, dementia care, collaborative care, caregiver-centered care

## INTRODUCTION

According to the World Health Organization (1) there are nearly 50 million people with dementia worldwide and projections indicate that this number could reach 82 million by 2030. The Alzheimer's Association (2) reported that over six million Americans and 747,000 Canadians (3) are living with Alzheimer's disease or a related dementia. Dementia contributes significantly to disability and dependence for older adults worldwide, and "it places a physical, psychological,



social, and economic toll on those with the diagnosis as well as their caregivers, families, and societies” (1).

Manifestations of dementia extend far beyond the person with the diagnosis. Individuals with dementia are increasingly dependent upon others as the illness advances and, thus, their care needs come to require the involvement and commitment of others, usually family members. In the United States, 83% of support provided to older adults comes from family, friends, or other unpaid caregivers (2). Older adults with dementia are more likely than those without dementia to have co-morbid conditions, such as heart disease, diabetes, and kidney disease, which compounds the complexity of their care needs (2). For these reasons, the care preferences of the person with dementia must be understood in combination with the preferences of their caregivers, and within the context of their family relationships and the social ecological contexts in which they are embedded. In 2021, the Alzheimer’s Association (2) estimated the cost of caring for those with dementia to be \$355 billion, including \$239 billion in combined Medicare and Medicaid payments, in addition to the estimated \$257 billion worth of care provided by family and unpaid caregivers.

Nearly three-quarters of those providing care to someone with dementia, one-third of whom are 65 years of age and older, expressed concern about maintaining their own health since taking on a caregiving role (2). Over ~30–40% of family caregivers report depression and 44% report anxiety (4). The ongoing stress of caregiving has also been linked to impaired sleep, increased hypertension, impaired immune function, slowed wound healing, and increased inflammation (2). While employment can be a relief, that is it can counter-balance caregiving strain at home, caregiver in Canada and the United States experience more caregiving-work conflicts and tend to reduce work hours or stop working as the dementia progresses (5–7). Financial strain adds to caregiver stress (8, 9). The most recent American Association of Retired Persons study found that on average family caregivers are spending 26% of their income on caregiving activities (9). Because the responsibility for providing care to someone with dementia places such a toll on those who do, an integral part of dementia care involves supporting and sustaining caregivers. With families providing the majority of dementia care, supporting caregivers has become a public health priority (10, 11).

Person-centered care has been widely adopted as the gold standard of care for older adults, including those with a dementia diagnosis (12, 13). As defined by the Institute of Medicine (14), person-centered care is that which “is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.” The provision of person-centered care to those with dementia becomes complicated, however, as the person’s dependence on family and friends increases to the point at which the needs and preferences of the person(s) providing care must also be considered in care planning. In an effort to call attention to the needs of family caregivers, Parmar et al. from Alberta, Canada (15–17), developed a comprehensive set of caregiver-centered competencies aimed at training healthcare professionals to better recognize and address the needs of caregivers. They coined the

term “care giver-centered” to specifically focus on a person- and family-centered approach to supporting caregivers as well as the people they care for. When the needs and preferences of more than one person are involved in a care decision relationship factors among those involved become an essential consideration in the care planning process. It was the co-authors’ mutual recognition of the narrow lens through which caregiver needs are commonly addressed in dementia care settings, in both the United States and Canada, that brought us together as collaborators on this project.

In this paper we propose a conceptual framework that applies principles of both the biopsychosocial and social ecological models to person-centered care for the person with dementia and the family member(s) who care for them as a way to illustrate the significant influence that family relational factors have on a patient’s and caregiver’s experience of dementia.

## HISTORY OF THE BIOPSYCHOSOCIAL MODEL AND DEMENTIA CARE

Engel (18) described the biopsychosocial (BPS) framework as “a scientific model constructed to take into account the missing dimensions of the biomedical model.” Originally proposed as a framework to shape diagnostic and treatment approaches to psychosomatic illness (19), Engel called on physicians to attend to the ways in which biology, psychology, and social issues contribute to the presentation of health and treatment response at the psychological, physical, and social levels of functioning (20). Since the seminal publication in 1977 (19), the biopsychosocial model has become an accepted clinical paradigm not only for medical education but also for professions including nursing, social work, psychology, and marriage and family therapy, and it is also the foundation upon which medical family therapy and integrated care were developed (21). The BPS has been applied to the art and science of medicine, to patient and physician experiences, and to myriad physical and mental illnesses.

There are few published reports on applications of the biopsychosocial model to dementia. In the United Kingdom, the biopsychosocial model was used by the National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (22) to inform the development of guidelines for clinical practice and evidence-based decision-making related to dementia care. Keady et al. (23) described how these guidelines aligned the biological, psychological, and social domains to manifestations of dementia symptoms but failed to address the physical symptoms and, hence, proposed the utility of a biopsychosocial-physical model of dementia. Spector and Orrell (24) proposed a working BPS model of dementia focused on the patient’s needs over the course of the illness. They differentiated between the biological and psychosocial factors that are fixed and those that are tractable in an effort to inform intervention strategies. In these three BPS applications the focus of care was limited to the needs of the person with dementia.

In addition to clinical applications, the BPS approach has also been applied toward understanding variations in family awareness of Alzheimer’s disease during the pre-diagnostic phase

of cognitive impairment. Clare (25) published a review of the models that explained variations in awareness of observable changes in people with early-stage Alzheimer's disease. The author concluded that understanding variations in awareness requires a BPS model of awareness that takes into account neuropsychological impairments and psychosocial responses by others, and that understanding both was essential for developing person-centered dementia care. Clare et al. (26) later tested a BPS model of awareness in early-stage dementia by gathering evidence regarding the relative contributions of neuropsychological, individual psychological, and social factors to measures of awareness. Their findings supported use of a BPS framework in that psychological and social factors, along with illness-related and neuropsychological factors, were found to significantly influence the degree of awareness. In a related effort Rogers et al. (27) conducted a review synthesizing qualitative research exploring family members' experiences of the pre-diagnostic phase of dementia to inform clinical practice. They found that family members engage in a "sense-making" process throughout the pre-diagnostic period. In line with findings by Clare et al. (26) they reported that families made sense of the changes they saw in the affected family member by observing, appraising, and reacting to changes and that the social network influenced their appraisals and responses to change. This set of papers illustrates the important role that families play in determining the timing of diagnosis and in shaping the narrative that ultimately informs the history of presenting illness at the point of diagnosis.

## BEYOND BIOPSYCHOSOCIAL: ADDING A SOCIAL ECOLOGICAL PERSPECTIVE TO DEMENTIA CARE

Engel (18) acknowledged the existence of two hierarchies in that "the single individual (person) is the highest level of the organismic hierarchy and at the same time the lowest unit of the social hierarchy." He also noted (18) that be it a cell or a person "nothing exists in isolation," and every system is influenced by the environment or "configuration of systems" of which it is a part. Herein lies our rationale for adding an ecological component as a necessary extension of the BPS approach in dementia care. In what follows, we begin by describing how Engel's model falls short in addressing the needs of the person in the context of their lived experience of dementia. Then we move on to illustrate how the social ecological model allows us to better understand the person with dementia within their family relationships and social networks, which helps to capture a more comprehensive picture of the person's individual and relational needs regarding dementia care. Then, acknowledging that dementia care is shaped by relational factors, and incorporating the caregiver-centered work of Parmar et al. (15–17), we call attention to the need for dementia care models to go beyond the BPS and into the relational level of the social ecological model of the family member(s) who provide care.

Around the time Engel introduced the BPS model, Bronfenbrenner (28) published his groundbreaking work,

*The Ecology of Human Development*, the premise of which is that human development is shaped by the interaction between an individual and their environment. This was the genesis of ecological systems theory and the social ecological model (SEM) that continue to be applied to understanding a host of social issues, including many related to public health and social determinants of health.

There are few publications focused explicitly on the integration of the BPS and social ecological frameworks. One such effort in health psychology integrated concepts from the BPS and ecosystemic models, including the SEM (29). They developed a "dynamic model of health" to explain the interactive elements of the BPS model and the social ecological approach to elaborate interpersonal dynamics within social environments that modulate influences on health. This study lends credence to our rationale for incorporating these two models to better capture relational elements that are currently missing in dementia care models.

Other applications of the SEM to dementia include the following. The Changing the Person, Changing the People, and Changing the Place Model developed training for caregivers to promote maximal independence in individuals with dementia during meal time (30). Cho et al. (31) used data from the multisite Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) intervention and applied a socioecological framework to determine the extent to which intrapersonal factors, intrapersonal processes and groups, and organizational factors could constrain or promote individual behaviors to influence the "positive aspects of caregiving." O'Shea et al. (32) used a social ecological framework to understand how various stakeholders perceived access to respite services and to explore the boundaries of public responsibility in relation to client care preferences. Wang et al. (33) used a social ecological approach to understand how individual, interpersonal, and community level factors influenced informal caregiver appraisals of their caregiving experiences.

Ecological systems theory has also been applied to the lived experience of people with dementia as addressed in this set of studies. Clarke et al. (34) found that by addressing individual and community needs, communities could develop services that promoted independence, control and choice, and enable people to re-narrate their lived experiences within their communities as purposeful. Gorska et al. (35) examined the emerging experience of people living with dementia and found that their potential to adjust to continuous changes is influenced by access to and quality of both personal and contextual resources which remain in a constant, transactional relationship to each other. They later found the process of adaptation to be one that involved active participation through ongoing, dynamic and non-linear interactions between the adaptive capacity of a person with dementia and the adaptive capacity within the environment (36). Together these studies indicate the importance and value of considering people with dementia and their needs within the relationships and contexts of their larger environments.

## CURRENT MODELS OF DEMENTIA CARE: BIOPSYCHOSOCIAL AND SOCIAL ECOLOGICAL CONSIDERATIONS

There are many published reports of effective, evidence-based dementia care models (37–42), all of which are interdisciplinary, collaborative, and address the BPS needs of patients with dementia. They are based in primary care, in geriatrics, or in specialty care practices; some have a home-based component; others are co-management models with primary care; all have case management services and collaborate with community providers; and some include palliative care. These models focus on providing accessible, person-centered, and socioculturally appropriate care, while improving health outcomes and reducing costs (41, 42). By acknowledging the complex interaction of cognitive, functional, behavioral, and psychological symptoms that contribute to decreased quality of life for the person with dementia and family caregiver(s), they largely call for health care professionals to address the BPS needs of the patient along with the caregiver's needs for dementia education and support. Boustani et al. (37) from the Healthy Aging Brain Center in Indianapolis, describe the need for care models that improve health outcomes for patient and caregivers through pharmacological and non-pharmacological interventions “specific to the dementia-related disability.” From our lens we perceive limiting the scope of assessment and intervention to “the dementia-related disability” as shortsighted in adequately addressing the course of a disease that is shaped so significantly by relational and ecological factors.

In most dementia care models the focus on the caregiver is limited largely to bolstering the caregiver with the goal of sustaining care for the person with dementia. The caregiver is viewed less often as a person with needs of their own or as a partner on the care team (43). More recently dementia care investigators have recommended that models specifically assess and address caregiver's support needs to better assist them in their caregiving role and to maintain their well-being. Queluz et al. (44) published results from a scoping review of 31 studies on needs of dementia caregivers. Choosing from among fixed-choice options, personal health (58% emotional health; 32% physical health) and receiving help from others (55%) were the most frequently endorsed caregiver needs. Queluz et al. (44) noted, however, that the investigators' concluding recommendations did not address the two most commonly cited needs but, rather, focused on information gaps and education needs of caregivers, the two needs most routinely addressed in clinical practice.

Leading dementia models use comprehensive assessments comprised of validated measures to guide care planning, including support for caregivers. Investigators of the MIND at Home program at Johns Hopkins University conducted a randomized controlled trial to test an intervention designed to systematically identify and address dementia-related care needs through individualized care planning, referral and linkages to services, provision of dementia education and skill-building strategies for caregivers, and care monitoring by an interdisciplinary team (38). The domains of need they

assessed included home and personal safety, general health care, daily activities, neuropsychiatric symptoms and legal concerns. At baseline the most frequently addressed unmet needs of those with dementia included personal and home safety, general health and medical care, meaningful activities, legal and advance care planning, and diagnosis of dementia. Caregivers most often received referrals for resources and education. The UCLA Alzheimer's and Dementia Care program also administers a comprehensive assessment of patient and caregiver needs that address domains that capture BPS needs of patients, and caregiver issues including caregiver strain, depression, and needs for services.<sup>1</sup> At the outset of the program referrals were most commonly made for support groups, wandering support, caregiver training, and medication adjustment (39). Neither of these programs assesses for relational histories or family factors that could influence the care plan or quality of life for the person with dementia or their caregiver(s).

In addition to addressing BPS concerns of the patient, the Healthy Aging Brain Care program also assesses caregiver needs, including depression, strain, burden, and physical and emotional strain. While this assessment does not address the quality of family relationships, it does address factors within the caregiver's social ecological system by addressing their living situation, other caregiving and competing responsibilities, worries, and sources of support.<sup>2</sup>

While these programs are all highly attuned to the dementia patient's needs and to the needs of the family member as caregiver, none addresses the quality of the relationships between the patient and the family caregiver(s), how they function as a family, or any past or present interpersonal safety or trauma-related concerns that could affect care plan implementation, quality of life, or health outcomes. In addition, following assessment, caregivers are often referred to other community resources to get their needs met and it is unclear whether there is coordination or communication back to the dementia care program regarding the outcome of those referrals. As Aldridge et al. (45) contend, each service often serves the family “in isolation” from each other as opposed to working collaboratively. They conclude that this often leads to a poor understanding of each other's roles in supporting the “collective complex needs of the family.” Further, O'Shea et al. (32) described this type of care as being embedded in a system “configured to deliver a biomedical model of care and which assumes non-medical care is a family responsibility.” While these models are all effective in doing what they are designed to do, the designs do not address understanding the needs of those with dementia and their family caregivers in a way that acknowledges the power of family relational dynamics in shaping the dementia or caregiving experience, clinical encounters, or outcomes of care.

<sup>1</sup><https://www.uclahealth.org/dementia/workfiles/for-physicians/Intake-Email-8.25.2020-fillable-NEW.pdf> (accessed July 17, 2021).

<sup>2</sup><https://www.capc.org/toolkits/implementing-best-practices-in-dementia-care/> (accessed July 17, 2021).

## A BIOPSYCHOSOCIAL-ECOLOGICAL, FAMILY-FRAMED APPROACH

Lyman Wynne, MD, PhD [(46), pp. 220–221] in reflections on conversations he had with his longtime colleague George Engel pointed out that Engel was “clear and explicit” in recognizing ways in which the system levels were different yet linked [(46), p. 221]. Engel (18) stated, “Each system implies qualities and relationships distinctive for that level of organization” and further argued that “in no way can the methods and rules appropriate for the study and understanding of the cell as cell be applied to the study of the family as family” [(46), p. 221;12]. Similarly, in no way can the methods for assessing dementia-related BPS factors of those with dementia capture the essence of the relationships and communities in which they are a part; nor can they capture the individual, relational, or social factors that influence the family member’s performance as caregiver. Thus, this is our rationale for focusing on the ways in which interactions within and between the individual and relational levels of a person’s social network influence the experience of dementia for the person with dementia and the family caregiver(s).

Family relational factors and dementia care outcomes have been examined. Relationship satisfaction prior to diagnosis was found to be negatively associated with caregiver burden in that caregivers with high satisfaction reported less burden and reactivity to memory and behavior problems, and better problem solving and communication skills (47). Caregivers reporting poor family functioning at time of diagnosis expressed higher ratings of strain and burden (48). Increased caregiver burden and strain were related to poor emotional responsiveness, problem solving, and communication (47) and to impairment in role functioning and emotional involvement (47, 49). Decades of research show family relational factors that adversely affect health include: high interpersonal conflict, low relationship satisfaction, poor problem solving skills, high levels of criticism and blame, intra-family hostility, poor family organization, inconsistent family structure, family perfectionism and rigidity, low family cohesion, lack of closeness, and lack of an extra-familial support system [(50), p. 204]. Protective factors include: good communication, adaptability, clear rules, mutual support, open expression of appreciation, commitment to the family, spending time together, good problem solving skills, and an extra-familial support system [(50), p. 205]. Yet family relationships are largely ignored in clinical settings.

## CASE PRESENTATION

The following case is presented to illustrate, using a biopsychosocial-ecological perspective, three different approaches to serving persons with dementia and their caregiver(s) in clinical practice.

**Presenting concerns:** Janice is an 85-year-old woman who lives independently in senior housing in the Canadian province of Alberta. In response to Janice’s increasing needs for support, Gwen, her daughter and primary caregiver, scheduled an appointment for them to meet with her mother’s Geriatrician

to discuss changes in Janice’s health and function related to her progressing dementia, and planned to discuss her own needs for support as well.

Gwen reported to the geriatrician that her mother’s decline had been steady since her last appointment, most notably in her short term memory such that she was increasingly losing items, struggling to recall recent events, forgetting names, and having difficulty finding words, managing complex tasks, and planning. She shared that her mother had developed paranoia and visual hallucinations over the past year during which she imagines that strangers are trying to get into her home to steal her treasured belongings. The hallucinations had increased steadily and had worsened over the past month now occurring multiple times per week usually at night. Gwen also reported that Janice calls her frequently asking for help, and she noticed her mother being more irritable, angry, and frustrated than she used to be. She shared that her mother wanders out of her room but has not gotten lost.

Gwen also noted a “quite rapid” decline in Janice’s function. Because she was no longer able to use the stove and had burned pots, she ultimately stopped cooking and depends on microwave-ready meals and easy snacks. Even with Gwen bringing her meals, however, Janice has had a 20 pound weight loss over the past year. Janice can still perform basic activities of daily living such as dressing, grooming, bathing, feeding, toileting, transfers and mobilization. She can still use the phone and does housekeeping and laundry on her own, but Gwen finds clothes soaked in urine in the laundry and believes that her mother has not bathed in a month. Gwen now manages her mother’s money, medical appointments, and medications, and does her shopping and other errands as well.

Janice’s neighbors and building management started to raise concerns to Gwen about her mother’s safety, which Gwen reported has greatly increased her own anxiety about her mother’s living situation. They reported that Janice is seen wandering around the facility at all hours and often checks in with other residents when she gets confused about day and time. There are times when she will knock on her neighbors’ doors asking for help while experiencing hallucinations. They know her well and reassure and redirect her but Gwen wonders how long they will be willing to do this. Janice adamantly denies needing assistance but Gwen was finally able to get her to accept homecare for help with medications. The agency recently informed Gwen, however, that Janice does not always open the door for the homecare attendants and that she sometimes calls them derogatory names and yells at them to “get out.”

**Concurrent problems:** While Janice has experienced urinary incontinence for years, she was managing on her own with pads and then protective underwear as the incontinence worsened. Gwen describes her mother’s bladder control as “good during the day” but notes that she “occasionally soaks her night clothes and bed during the night.” Janice also has occasional bowel incontinence and Gwen noticed that her pericare had declined and shared that she had found smeared stool around the toilet. The geriatrician also expressed concern about Janice’s sensory deprivation noting that she is legally blind due to macular degeneration and that she suffers from bilateral hearing loss and



has been unable to manage hearing aids on her own. Janice's other medical conditions include hypertension, osteoporosis, osteoarthritis, and hypothyroidism. She never smoked, rarely consumes alcohol, and gave up driving 3 years ago because of her vision loss.

**Mental exam:** The geriatrician noted that Janice was alert and cooperative and that she needed a pocket talker to hear. She scored 24/30 on the Mini-Mental State Exam (51) and 18/30 on the Montreal Cognitive Assessment (52), both of which indicate "mild dementia." The Clock Drawing Test (53), a measure of spatial dysfunction and neglect, was abnormal. She correctly placed the numbers on the clock face but could not tell time. She had problems with orientation and displayed both short and long term memory deficits. Language skills were intact other than occasional word finding problems. She appeared anxious and got easily irritated. She needed reassurance to complete the assessment. She was occasionally distracted by visual hallucinations (e.g., she saw people in the room and wanted them chased away). She denied symptoms of depression. She had poor insight into her cognitive and functional decline and displayed poor mental reasoning when it came to supports needed to help her with her health and housing. She overestimated her abilities and did not recognize the degree of supports being provided to her. She acknowledged that her daughter provides some help but said she could manage without it. She expressed annoyance with having homecare.

**Physical exam:** No apparent distress.

**Family and social history:** Janice completed education through Grade 8 and worked as a secretary until she had children. She has been widowed for 20 years after having been a caregiver to her husband who died of cancer. She has 3 daughters, 1 son, and 8 grandchildren. Gwen, the youngest, her primary caregiver, and "the baby" of the family, is married, has 2 children, and lives 10 min away. Janice's son, Jack, is an accountant who lives out of town, helps with higher level financial management such as taxes, and is a source of emotional support for Gwen. Janice often mentions that Jack "leads a busy life with work and family" as an explanation for his infrequent visits. Her two older daughters are both married, retired, and live in other provinces. They check in about their mother periodically and visit once a year. Neither of the two older daughters is close to Janice or Gwen with the emotional distance rooted in their shared belief that their mother favored their two younger siblings when they were growing up. Gwen and Jack have remained close and frequently discuss their mother's deteriorating health and function. Janice has lived in her current residence, a subsidized senior housing facility, for the past 30 years. She has limited finances, including her husband's pension and her own, and she relies on her children to assist with money as needed.

**Patient's values and beliefs:** Janice does not want to leave her home. She is feisty and wishes to remain independent. She is fond of her belongings and takes pride in them—e.g., furniture, paintings, pictures, collectibles, etc. She believes that she raised her children well and gave them a good education, and she now expects reciprocity. She acknowledges the support provided by her daughter but is not particularly empathic toward her stress.

**Medical and legal issues:** Janice designated Gwen and Jack as the agents in her Personal Directives and Enduring Power of Attorney (EPOA), respectively. The EPOA was activated at the time it was established. Janice's Goals of Care Designation, a medical order used in Alberta to describe and communicate the general focus of care including the preferred care location, indicates that goals and interventions are for cure or control of illness. Her goals exclude the option of ICU care, while transfer to an acute care facility may be considered if required for diagnosis and treatment.

**Caregiver stress:** Gwen is committed to caring for her mother and determined to support her at home. She reported that she had promised not to relocate her to a "nursing home." However, she admits to feeling "very stressed" caring for her mother. She is the only one in town and has taken over the majority of the responsibilities. Janice is quite demanding and calls her day and night asking for help. She gets easily irritated and angry with Gwen who has already reduced her hours at work by going part-time. Gwen believes at this rate she will have to quit work all together. This adds to her stress because she feels guilty about harming her family's financial situation. She and her husband annually spend \$6,000 subsidizing her mother's housing, food, and health care supplies. Gwen is keenly aware that their daughters are approaching college age and that this is not the time to leave the workforce. She feels that her life is "on hold." Her husband and children are supportive and help however they are able. She resents the lack of support from her sisters but finds her brother more supportive as he provides her with emotional support and helps to support their mother financially. At the same time she feels he could visit more often. She shared that caregiving is taking a toll on her health as she is experiencing panic attacks, insomnia, poor concentration, feelings of guilt, and chronic migraines, in addition to having emotional and physical symptoms associated with perimenopause.

## IMPRESSION AND INTERVENTIONS

**Patient-centered:** Janice meets criteria for Mixed Dementia (Major Neurocognitive Disorder) with Behavioral Psychological Symptoms of Dementia, with impairments in memory, insight, judgment and executive function. The neurobehavioral issues include easily irritability and anger, verbal abuse and hallucinations of a persecutory nature. The sensory deprivation due to macular degeneration and hearing loss could be playing a role.

Her dementia is approaching moderate severity with a loss of function primarily in instrumental activities of daily living. Her function could be maintained with increased homecare and support from her daughter. She needs monitoring of medications, caloric intake, and weight and needs to be encouraged to drink fluids as she is at risk for malnutrition and dehydration. She also needs reminders to take a shower and tend to periodic pericare. Her refusal of homecare is problematic. The Geriatrician reviewed the options with her daughter, including self-managed care and having a consistent care provider and overnight care. Gwen agreed to install a locked box to give



**TABLE 1A |** Examples of biopsychosocial and social ecological considerations for a person with dementia: the case of Janice.

**Identifying Information:** Janice is an 85-year-old woman with advancing dementia who lives in Alberta, Canada

**Reason for Assessment:** Dementia requiring support for care planning and medical intervention

**Dementia Diagnosis:** Mixed Dementia (Major Neurocognitive Disorder) with Behavioral Psychological Symptoms of Dementia

Biological/functional	Psychological/behavioral	Social
<b>BIOPSYCHOSOCIAL CONSIDERATIONS</b>		
<ul style="list-style-type: none"> <li>Steady decline in cognition &gt;2–3 years</li> <li>She scored 24/30 on the MMSE and 18/30 on the MOCA; abnormal Clock Draw Test; observed impairments in memory, insight, judgment and executive function</li> <li>Medical conditions: hypertension, osteoporosis, osteoarthritis, hypothyroidism</li> <li>Sensory deprivation: legally blind due to macular degeneration; hearing loss with declining ability to use hearing aids</li> <li>Urinary (urge) incontinence, worse at night; bowel incontinence, occasional</li> <li>Steady, now rapid, functional decline &gt; 1 year; can manage dressing, feeding, transfers, and mobilization; requiring assistance with toileting, bathing, grooming</li> </ul>	<ul style="list-style-type: none"> <li>Experiencing episodes of paranoia</li> <li>Experiencing persecutory visual hallucinations &gt; 1 year, increasing in severity</li> <li>Has poor insight regarding her cognitive and functional abilities; overestimates her abilities and does not recognize the degree of supports being provided to her</li> <li>Becomes irritable easily and expresses anger and frustration regularly</li> <li>Consistently refuses idea of homecare</li> <li>Refuses to let attendants into her home at times</li> <li>Wanders around housing complex</li> </ul>	<ul style="list-style-type: none"> <li>Was born and raised in Canada</li> <li>Completed Grade 8 education</li> <li>Worked as a secretary before children</li> <li>Was married and has 3 daughters, 1 son, and 8 grandchildren</li> <li>Widowed for 20 years; had cared for her husband who died from cancer</li> <li>Has lived independently in subsidized housing for 30 years; has limited finances</li> <li>Seeks support from neighbors</li> <li>Can no longer use stove. Relies on microwave-ready meals and snacks</li> <li>Can no longer manage finances, medical appointments, medications, shopping</li> <li>Stopped driving 3 years ago (vision loss)</li> <li>Safety risks with stove and wandering</li> <li>Hygiene concerns (e.g., smeared feces around toilet, urine-soaked clothing in laundry)</li> <li>Has medication management assistance</li> </ul>
<b>Individual level</b>		
<b>Relational level</b>		
<b>SOCIAL ECOLOGICAL CONSIDERATIONS</b>		
<ul style="list-style-type: none"> <li>Goals of care per patient's documented wishes: Supportive care, symptom management and comfort measures only</li> <li>Patient does not want to leave her home</li> <li>Is strong-willed and values independence</li> <li>Cherishes and takes pride in her home of 30 years (i.e., her decorations, furniture, paintings, pictures, collectibles etc.)</li> <li>Believes that she did well raising her children and giving them a good education and expects reciprocity</li> <li>Overestimates her abilities and does not recognize the degree of supports being provided to her</li> <li>Lacks capacity/Personal Directive regarding domains of health and accommodation to be activated</li> </ul>	<ul style="list-style-type: none"> <li>Janice has 3 daughters, 1 son, 8 grandchildren</li> <li>Youngest daughter, Gwen, is her primary caregiver who lives 10 min away. She is married, has 2 children, and has reduced her work hours to accommodate her mother's needs</li> <li>Patient's son, Jack, is an accountant, lives in another province and helps with higher level money management such as taxes. He leads a busy life with work and family.</li> <li>Janice's 2 older daughters, also married, live in other provinces. Both retired they check in with caregiving daughter periodically about their mother and visit her once a year. They are not close to their mother or sister as they felt their mother favored the their two younger siblings when they were growing up</li> <li>Gwen and Jack have remained close and discuss the issues and care plans around their mother's deteriorating health and function</li> <li>Gwen is the agent in her Personal Directive (i.e., Advance Directive) and Jack is agent for the Enduring Power of Attorney (EPOA), which became effective on the date it was established</li> <li>When the Personal Directive was recently enacted Gwen was granted authority to make decisions for her mother regarding health and accommodation (housing)</li> <li>Janice checks in with other residents around day, time etc. She will often knock on her neighbors' doors asking for help with her hallucinations. They know her well and reassure and redirect her</li> <li>Janice and Gwen have good relationships with patient's primary care physician, a geriatrician</li> </ul>	

access to the homecare attendants who will also assist her hearing aid use. The case manager has good rapport with Janice and will work with her to accept help. The hallucinations need aggressive treatment because the patient is experiencing them frequently and acting on them. Increased Quetiapine to 50 mg qhs and 12.5 mg q6h prn. Homecare attendants and her daughter will monitor for side effects. Bloodwork ordered through home collections to rule out anything acute.

Janice lacks capacity to make decisions in the domains of health and accommodation, and is making decisions that are putting her in harm's way. The Personal Directive needs to be enacted which will give Gwen the authority to make decisions for her in these two domains.

**Caregiver-centered:** The Geriatrician also addressed Gwen's stressors. Following at-length discussion Gwen agreed to referrals for emotional and psychological support, and for system navigation. She also agreed to contact her primary care physician to address her mental and physical health concerns. She requested a family conference with her siblings and the Geriatrician asked the case manager to arrange one to discuss the possibility of more family cohesiveness in providing for Janice's care and decision-making. Gwen also expressed an interest in learning to set limits with her mother and agreed to a social work referral to discuss strategies. She acknowledged that enacting the Personal Directive may increase her sense of control.

**Goal: To support Janice in her current residence:** Based on previous conversations and verified again at this appointment, the Geriatrician ascertained that Janice's strong preference is to remain in her current residence. Janice expressed that her greatest fear is being evicted and that she "wants to stay there at all costs." Her daughter acknowledged that she would like to honor her mother's wishes.

## VIEWING THE CASE THROUGH THE BIOPSYCHOSOCIAL-ECOLOGICAL, FAMILY-FRAMED LENS

The biopsychosocial and social ecological factors associated with Janice and Gwen, as presented in the case, are delineated in **Tables 1A,B**, respectively. **Figure 1** illustrates how most dementia care models, based upon what they assess as described earlier, view the needs of the person with dementia (PWD) and their family caregivers (FCG). By and large they address the BPS needs of the PWD relative to dementia, and consider the FCG's needs in relation to maximizing support of the PWD's plan of care by addressing needs for dementia-related education and support.

**Figure 2** illustrates a model that acknowledges that the PWD (Janice) and FCG (Gwen) occupy distinct social ecological systems albeit with minimal overlap in this case. The caregiver-centered competencies developed by Parmar and colleagues (9–11) reflect this understanding that one cannot know best to support a caregiver by assessing the person with dementia. In this figure the BPS factors are included within the individual levels for Janice and for Gwen. For Janice, her Geriatrician, daughter Gwen, and son Jack plan for her care and increase services as needed to allow her to remain in her home as she wishes. Neighbors in the housing complex redirect her as needed. Her other daughters visit occasionally. This figure also elucidates the contextual factors which facilitate and impede Gwen's role responsibilities and well-being. It shows the resources and relationships she has available within her social network—i.e., husband, children, health care professionals, friends, aging service providers and support networks, friends, and colleagues. While this figure identifies the factors that likely influence the experiences of dementia for both Janice and Gwen, it does not offer much in terms of the ways in which the interpersonal relationships or family dynamics affect the well-being of either or their experience of dementia. This figure is akin to looking at a family photo album to see who is in the family but without access to a companion journal with detailed accounts of the family history or relational dynamics that shape the way its members function and relate to one another today.

**Figure 3** identifies the "family-framed" domain of the biopsychosocial-ecological model that is generally missing from current dementia care practices. This figure illustrates that the PWD and the FCG each occupy a separate socioecological system, as in **Figure 2**, but also reflects the need to understand the important relationships for each individual as well as the relationship dynamics between the PWD and FCG. The

ultimate goal of family-framed dementia care is for healthcare providers to know and understand the person with dementia and family caregiver(s) within the context of their family relationships in order to develop a plan of care that meets the biopsychosocial needs and wishes of the person with dementia; and considers the needs, wishes, and resources of the family caregiver(s) so that the care plan will be feasible, likely to be implemented, and promote the safety and well-being of all involved family members. The relational context, depicted by the circle connecting the two ecosystems, represents factors including but not limited to: family of origin experiences and expectations regarding health, illness, dementia, and caregiving; relationship histories of involved family members; relationship quality and dynamics between the PWD and the FCG(s); motivations for and degree of commitment to caregiving; power dynamics and decision-making authority regarding health care and finances; and family trauma, mental health, substance misuse, and/or abuse history (54). Applying a family frame to Gwen's individual and relational considerations, one might discover that: (1) she has responsibilities for running the household while her husband travels, tends to the needs of their children, contributes needed income from her job, and serves as primary caregiver for her mother despite having her own medical and behavioral health symptoms that interfere with her ability to function as needed across various roles; (2) her family relationships have been strained by her caregiving responsibilities and she is overwhelmed by feelings of depression, anxiety, guilt, and failure; and (3) caregiver stress is not her only health concern and that those supporting her in restoring her mental health include her husband, children, her GP/PCP, her behavioral health provider, her mother's aide and neighbors, other service providers, her employer, and her work colleagues. As this set of supports is instrumental in helping Gwen, they also indirectly support Janice and her wish to remain in her home.

As in most models of dementia practice, the Geriatrician in this case is responsible for managing Janice's symptoms and care plan, and for assisting Gwen by activating Janice's Personal Directive and for helping Gwen by identifying services to meet her mother's needs for things she is unable to provide herself. Aside from referrals for caregiver support, the physician's responsibility for the caregiver's needs typically ends there. Gwen's health symptoms, however, impair her ability to provide optimal care to her mother and may impede her capacity to carry out her plan of care. While the Geriatrician is providing all of the support possible for Gwen given that she is not the patient of record, Janice's desire to remain at home is contingent upon available resources and her daughter's ability to provide or arrange for care to meet the needs that go beyond what the Geriatrician and housing facility can provide.

In our current bifurcated models of care in which the needs of the patient and caregiver are typically not addressed side by side, it is unclear, for example, who holds the responsibility to ensure that the caregiver is capable of meeting the patient's needs or if the patient's preferences are unrealistic. In most practice models the physician responsible for their patient's dementia care would likely assess for caregiver stress and then

refer the daughter, as this physician did, for caregiver support, education, and assistance with navigating the social service sector. This Geriatrician, with a caregiver-centered and family-framed approach, went two steps further by enlisting the support of a case manager to arrange for a family meeting with the hope of soliciting more assistance from the patient's other children, and by obtaining social work assistance to help the daughter set appropriate limits with her mother for the sake of preserving the caregiver's health.

## INTEGRATING RELATIONAL CARE INTO DEMENTIA CARE: TEAM TRAINING AND TOOLS

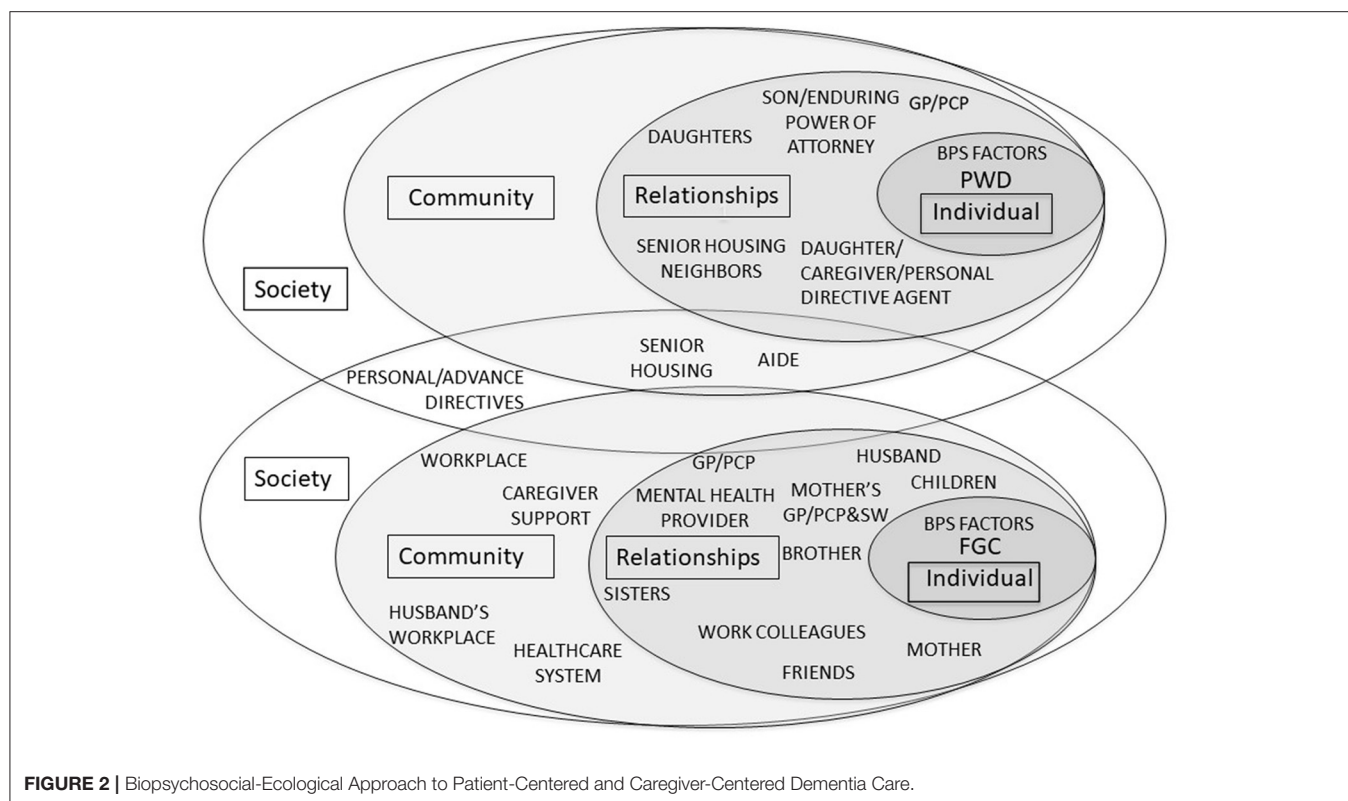
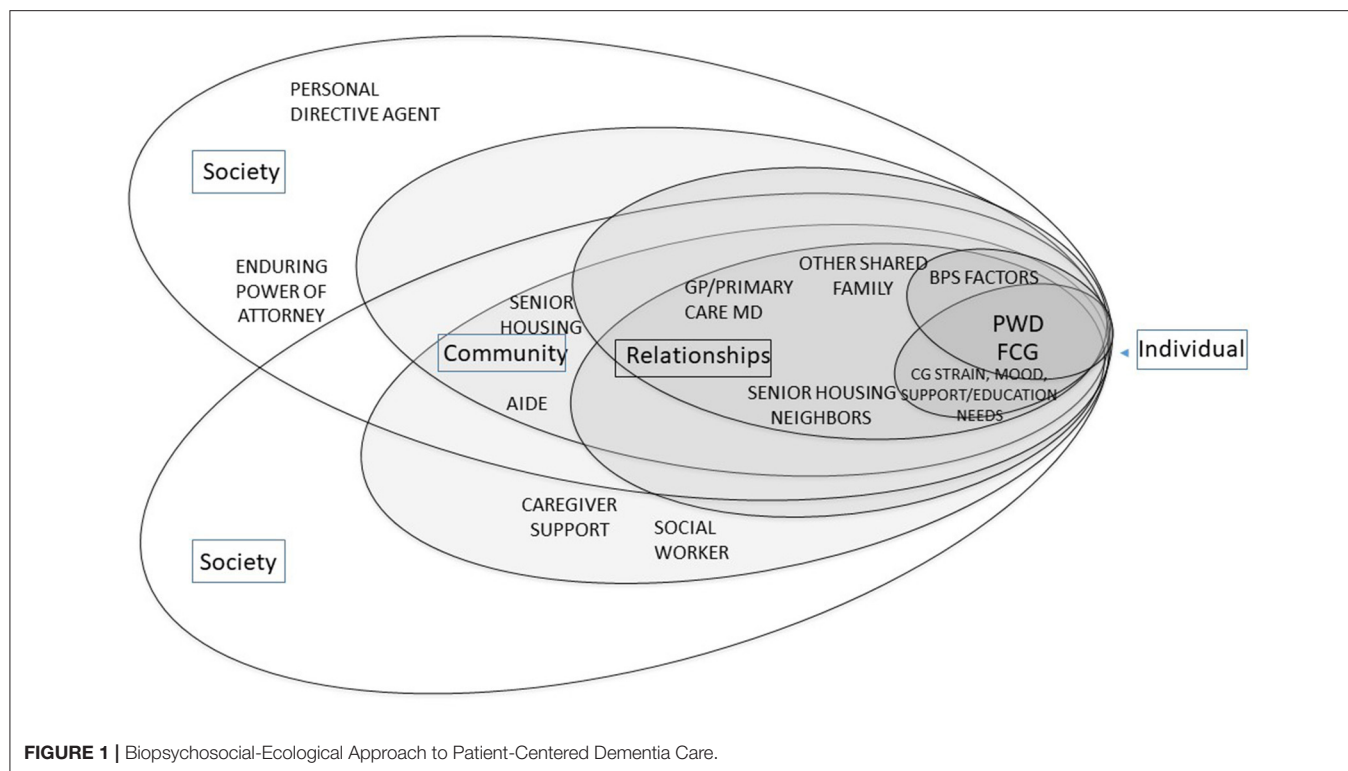
Family caregivers often report that their needs are often overlooked in medical settings. Fisher et al. (43) reported on a symposium conducted in Canada to identify factors that affected care provision to family caregivers by healthcare professionals. A primary finding was that family

**TABLE 1B |** Examples of biopsychosocial and social ecological considerations for a family caregiver: the case of Gwen.

**Identifying Information:** Gwen is a married 45 year old woman with two children, a job, and responsibilities as primary caregiver for her 85 year old mother with advanced dementia who lives nearby in Canada

**Reason for Assessment:** Caregiver stress

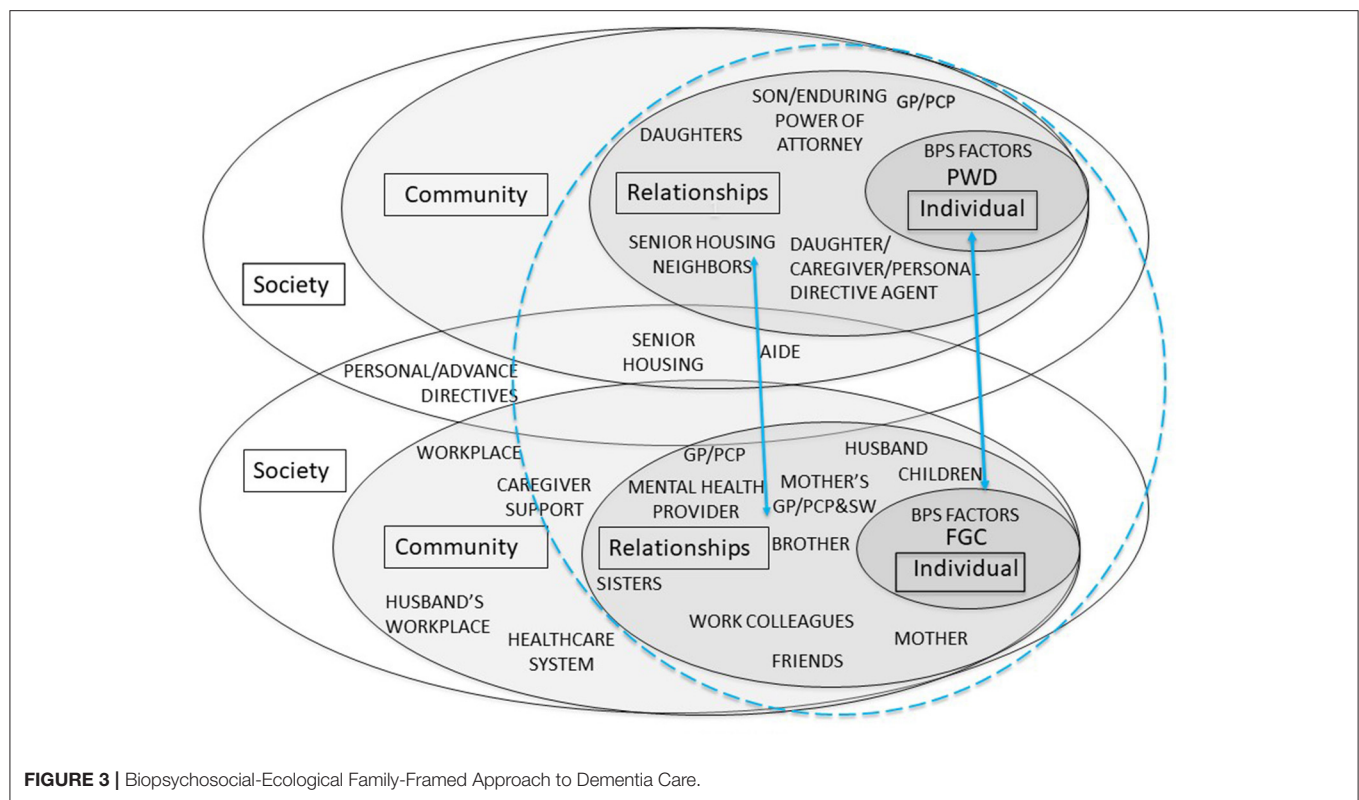
Biological/functional	Psychological/behavioral	Social
<b>BIOPSYCHOSOCIAL CONSIDERATIONS</b>		
<ul style="list-style-type: none"> <li>Symptoms of depression (e.g., difficulty falling and staying asleep, low energy, poor concentration, feelings of guilt and failure) increasing in frequency and intensity since her mother's care needs increased</li> <li>Symptoms of anxiety (e.g., fatigue, poor concentration, heart palpitations, occasional panic attacks) increased as concern for her mother's safety arose</li> <li>Medical conditions: hypertension, chronic migraines, perimenopause</li> </ul>	<ul style="list-style-type: none"> <li>Has been taking more sick days off from work and worries about losing her job</li> <li>Stopped playing in the volleyball league she and her husband always enjoyed and looked forward to each summer due to fatigue and headaches</li> <li>Relies on her two high school aged children to take care of things at home while she tends to her mother's needs</li> <li>Formerly a proud multitasker, she now focuses only on one thing at a time and gets anxious when asked to change her focus without notice</li> <li>Feels disconnected from her husband and children and they feel disconnected from her too</li> <li>Has a hard time accepting help from friends</li> <li>Lives with anxiety, sadness, and guilt that her mother's condition will deteriorate and that she will have to make the decision to move Janice from the home she cherishes to a facility with more care.</li> <li>Fears losing her job and related income</li> </ul>	<ul style="list-style-type: none"> <li>Was born and raised in two-parent household in Canada</li> <li>Married for 20 years, two children</li> <li>Employed as a dental hygienist part time</li> <li>Husband travels occasionally for work</li> <li>Has a small, close circle of friends</li> </ul>
<b>Individual</b>		
<b>Relationships</b>		
<b>SOCIAL ECOLOGICAL CONSIDERATIONS</b>		
<ul style="list-style-type: none"> <li>Mother's geriatrician set goal to reduce caregiver's stress and refers her to meet with a social worker to learn about care options for her mother</li> <li>Caregiver "misses her former self and her family"</li> <li>Husband encourages caregiver to see her primary care physician and offers to attend visit with her</li> <li>Primary care physician's goals for Gwen are to reduce symptoms of anxiety and guilt, reduce the frequency and severity of her migraines, and manage physical and psychological symptoms associated with perimenopause. Recommends medications and provides a referral to a behavioral health specialist for psychotherapy</li> </ul>	<ul style="list-style-type: none"> <li>Primary caregiver for her mother with whom she is very close.</li> <li>Is married, has 2 teenage children, and has reduced her work hours to accommodate her mother's needs</li> <li>Close relationship with her brother who is an accountant, lives in another province and helps their mother with higher level money management such as taxes. The two are close and discuss plans regarding their mother's deteriorating health. He has limited ability to provide in-person support for their mother.</li> <li>Distant relationships with two older sisters, also married, who live in other provinces and visit their mother once a year.</li> <li>She is the agent for mother's advanced directive (i.e., Personal Directive) and her brother is agent for the Enduring Power of Attorney (EPOA), which is in effect</li> <li>She was recently granted authority through her mother's Personal Directive to make decisions for her mother regarding health and accommodation (housing)</li> <li>Has a good relationship and relies on her mother's geriatrician and social worker for support and guidance</li> <li>Is reluctant to seek mental health care because it is "one more thing to do" and will "take a lot of energy"</li> <li>Her husband and children express relief and hope when she decides to seek care for herself and realign her priorities</li> <li>Employer supports short term medical leave from job to restore her health; caregiver feels relief for time to focus on her health and grateful for her colleagues' willingness to cover in her absence</li> </ul>	



caregivers require more support than they usually received from healthcare professionals. This was attributed to a number of factors, including a lack of awareness and

undervaluing family caregivers; system fragmentation, engrained healthcare professional practices and attitudes; policies limiting information-sharing with family caregivers;





a lack of caregiver assessments; poor communication; a lack of health workforce training regarding the delivery of emotional support to family caregivers and navigation of family dynamics; and inadequate knowledge of conditions impacting older adults.

Assessment of relational factors, while critical, constitute a time-consuming exercise that doesn't fit easily into a busy medical practice. Years ago Engel (18) pushed back against critics who argued that the BPS model increases demands on the physician and countered that "the model does not add anything to what is not already involved in patient care." Physician perceptions of the time involved in providing comprehensive BPS care have not changed much since Engel's time (42, 55). Hinton et al. (55) reported perceptions of providers from academic medical centers, managed care, and solo private primary care practices regarding challenges managing behavioral symptoms of patients with dementia. They identified insufficient provider time, inadequate reimbursement, poor access to dementia care expertise and community resources, lack of adequate communication across the various medical, social and community dementia care providers, and the absence of an interdisciplinary dementia care team as contributing factors. The investigators concluded that "the current operational structure of primary care is not prepared to manage the biopsychosocial needs of patients suffering from dementia." They called for more effective educational interventions for families and physicians as well as structural changes to meet the needs of patients and their families.

The efforts needed to incorporate relational care into medical practices are akin to those currently evolving to integrate assessment of social needs and social determinants of health (SDOH) into health care as a way to improve health outcomes. Healthy People 2030 (56) includes "interpersonal relationships" within the SDOH domain of "Social and Community Context" with the justification that "people's relationships and interactions with family, friends, co-workers, and community members can have a major impact on their health and well-being." The National Academies of Sciences, Engineering and Medicine (57) released a report that investigated the feasibility of bringing social care into health care. While there is agreement on the need for healthcare to address these social factors there is no clear directive as to whose responsibility it is to carry it out or to pay for it. Implementation is further obstructed by high physician burnout rates and the fact that care and services provided by those who could support these functions are often not reimbursable (57). One small step in this direction in dementia care in the United States was legislation that enabled Medicare to reimburse physicians for care plan services that support addressing the needs of those with dementia and their family caregivers in some limited but important ways (58).

**Interprofessional training:** Efforts toward establishing a foundation for interprofessional education in dementia have been steadily increasing (41, 59–62). Some focus on the disciplines that should be involved (41), the core topics required (41), and key elements required for effective interprofessional

collaboration (61). A number of programs target students across health care professions (62–64). Targeted outcomes have included improvements in student attitudes toward interprofessional education (62–64); knowledge of dementia (62, 63); collaborative interprofessional capabilities and client-centered mindset (64); and confidence (62).

Dreier et al. (41) identified the following as core topics to ensure successful interprofessional collaboration: early diagnosis; post-diagnostic support; advanced care planning for patients and caregivers; and effective collaborative care. They also proposed minimum standards for representation by discipline and recommended that team leadership and care coordination should include primary care physicians along with nurses and/or social workers. Other professions that would enhance collaborative dementia care include behavioral health providers, pharmacists, physical therapists, occupational therapists, and speech therapists. Jennings et al. (61) identified core themes for interprofessional dementia education to include: professional roles and responsibilities, with an emphasis on the post-diagnostic stage of illness; team collaboration; knowledge of dementia; and interprofessional communication skills.

The biopsychosocial-ecological family-framed approach to dementia care as proposed herein would require additional domains of interprofessional education, including a general understanding of how family systems, relationships, and dynamics affect the lived experience of dementia for those with the diagnosis and those who care for them (54); proficiency in administering a comprehensive family assessment to understand the strengths, and resources (65); knowing when to refer the patient and/or family caregiver(s) for behavioral health services or family therapy (66); and evaluating the needs of the family caregiver(s) to determine if they are willing, capable, and have the resources needed to provide the required support while maximizing their own health and well-being (17).

**Tools to support interprofessional education and relational dementia care:** Two tools were specifically developed to support interprofessional education regarding a BPS approach to dementia. The Biopsychosocial (BPS) model of dementia tool (24) was designed to encourage staff to develop personalized interventions and treatment plans for people with dementia. Revolta et al. (67) reported findings from a feasibility study addressing the impact of training staff to use the BPS model on skills, including formulation, attitude toward dementia, and sense of role competence. Similarly the Bio-Psycho-Social-Dementia-scale (68) is another validated tool appropriate for assessing family and other contextual factors that have the potential to affect care and illness experiences for patients and families. This tool was developed to rate and improve biopsychosocial functioning in dementia care, and also to facilitate interdisciplinary collaboration, promote assessment, and merge interprofessional strengths toward development of a heterogeneous team.

An essential tool to promote a biopsychosocial-ecological family-framed approach to dementia care is the shared electronic health record. Functionality that would allow community providers to which health care professionals refer those with dementia and their caregivers in support of social or relational

needs would help to bridge the chasm that currently exists between health and social service providers and could potentially allow for more coordination among providers caring for both the PWD and the FCGs.

## DISCUSSION

Family-framed dementia care calls for health care professionals in clinical settings, regardless of discipline, to meet the needs of the person with dementia and their family caregivers by understanding their needs and preferences within the context of the family structure, dynamics, and relationships. Relational dementia care is rooted in family systems theory (69) which posits that individuals cannot be understood in isolation from one another and that families are systems of interconnected and interdependent individuals. A relational approach to dementia care acknowledges that a dementia diagnosis often represents a significant life event for a family as it generates ripple effects far beyond the symptoms of the one diagnosed. Because a person with dementia will come to rely on the support of others, a care plan must address the needs and preferences of the person with the diagnosis as well as those of the family caregivers. Dementia care at the family level is relational, transactional, and often delivered in ways that reflect the nature and quality of family relationships. An awareness of relational influences help clinicians develop safe, effective, and sustainable care plans.

Family-framed, relational care does not detract from person-centeredness. Either the person with dementia, the family member, or both together can be the target of care. However, because of the relational nature of the caregiver/care-receiver relationship, there are times when shared needs would place the dyad or family at the center of care as in **Figure 1**. At other times, as depicted in **Figure 2**, their needs may be at odds. In both of these instances, addressing the needs of the dyad requires an understanding of relationships. Without doing so, the needs of one party may be inadvertently placed in opposition to those of the other.

A family-framed approach encourages clinicians to recognize that information shared by a patient or family member is frequently shaped by relational influences. In considering the role that family members generally play in dementia care—i.e., informant, interpreter, and advocate—limited awareness of family dynamics may preclude clinicians from understanding how those relationships influence not only the patient information that family members choose to share, but also how they interpret and communicate clinical information to the patient and other family members. Relational factors also influence whether and how care plans are implemented which inevitably affects patient outcomes.

This biopsychosocial-ecological model illustrates that the bifurcation of the person with dementia from the family caregiver results from chasms that exist between the biopsychosocial needs of the person with dementia and their social ecological context, and between the social ecological contexts of the person with dementia and that of the caregiver(s). In addition, the overall responsibility for the well-being of the patient and that of each caregiver are parsed across different providers in different systems that align with the biopsychosocial model (i.e., medical care, behavioral health care, and social services).

The personal physician of the person with dementia and the physician for each family caregiver likely address the medical and psychosocial needs of their respective patients. They are less equipped, however, to address the relational aspects that affect the caregiving process or the health status of any of the involved parties.

Engel (18) believed that “clinical study begins at the person level and takes place within a two-person system, the doctor-patient relationship.” We contend that for dementia care it goes beyond a two-person system in that it also includes the patient’s family, however defined, a relationship between the doctor and the family member(s) who provide care, and an understanding of the social and relational contexts in which they are embedded.

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## AUTHOR CONTRIBUTIONS

CP proposed the concept of family-framed care, suggested placing it within the context of the biopsychosocial, social ecological models, assumed primary responsibility for drafting the manuscript, created the figures and tables, and applied the framework to the case. SA and JP reviewed the conceptual model and affirmed that it was relevant for application to their work in Canada with caregiver-centered care, both conceptually and clinically. SA contributed to the literature review and intellectual content and reviewed and revised the conceptual framework and manuscript for clarity and consistency. JP prepared the case presentation. All authors contributed to the article and approved the submitted version.

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# Personalizing the BioPsychoSocial Approach: “Add-Ons” and “Add-Ins” in Generalist Practice

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Generalist practitioners often find interacting with patients deeply satisfying and joyful; they also experience encounters that are challenging and complex. In both cases, they must be aware of the many issues that affect the processes and outcomes of patient care. Although using the BioPsychoSocial approach is an important, time-tested framework for cultivating one’s awareness of patients’ presenting concerns, recent developments suggest that additional frames of reference may enhance communication and relationships with patients. In this article, we describe several additions to the BioPsychoSocial approach, considerations we call “add-ons” and “add-ins”. We invite generalist practitioners and, indeed, all health care practitioners, to consider how they can improve their ongoing care of patients by personalizing these and other additions in their day-to-day work with patients.

**Keywords:** biopsychosocial models, general practitioners, medical education, medical philosophy, physician-patient relations, primary care, systems theory

## INTRODUCTION

Based on systems theory and later complemented by patient- and relationship-centered care, the BioPsychoSocial (BPS) approach has become an important part of medical practice and medical education, especially among generalist practitioners (1–4). The approach is applicable as a way of conceptualizing, organizing, and addressing the physical, emotional, and social factors that influence how patients experience and describe their presenting concerns. Although not without its critics (5–7), and certainly not limited to generalist practice alone (8–10), the BPS approach has become one of the most important—some might suggest *the* most important—unifying model in generalist medicine over the last four decades (11).

Much has changed in generalist medicine since mention of the value of systems theory to patient care and publication of the seminal paper on the BPS approach (12, 13), which appeared in *Science* in 1977 (1). Significantly, scholars have established the overall importance of generalist principles and practices to highly functioning health care systems and improved population-based health care outcomes (14, 15). Much has changed in respect to the BPS approach, as well. From its origins as a theoretical approach to patients presenting principally with Somatic Disorders [now also referred as Medically Unexplained Symptoms (MUS) (16), Bodily Distress Syndrome (BDS) (17), or the patient-centered acronym PRESSS (Physical Reaction to Emotional Stress of Some Sort (18))], the BPS approach has sequentially emerged as a key element in both Patient-Centered Medicine and Relationship-Centered Care (19–21). The approach has also found adherents beyond generalist

practice, and clinicians in a wide variety of specialties and sub-specialties (as well as many other health care professionals) have spoken to its utility in attending to patient concerns (8–10, 22, 23). Research into the BPS approach has evolved significantly over the years, and many evidence-based and evidence-informed studies have confirmed its benefits in clinical practice (24–26).

Nonetheless, much remains the same. Due to cultural and economic forces within medicine that prioritize site-specific technological interventions and highly-remunerative patterns of practice over holistic approaches to patient care (especially in countries that are highly dependent on for-profit models of health care, such as United States), generalism has struggled to find its place as a foundational element of medical education and practice (27). Additionally, theories that undergird such practice, including the BPS approach, continue to languish in the shadows of the dominant, strictly biomedical understanding of medicine. Even among generalist practitioners, the BPS approach remains undervalued relative to the more traditional linear methods of diagnosis and treatment (28). In many educational institutions, the BPS approach is manifestly far from being fully implemented; it is unmistakably given lip service, glanced over, or simply ignored in the face of a biomedically-focused pedagogical paradigm (26).

What can be done? Motivated by our (1) mutual misgivings regarding the traditional enculturation of medical students and residents away from thinking holistically and systemically, (2) recognition of the importance of the BPS approach to generalist practice, and (3) firm belief of the approach's positive influence on patients' health, we suggest it is time to reconsider how generalist practitioners understand and use the approach. We base our considerations on 70 years' combined direct clinical experience in and research observations of generalist practice—one of us is a seasoned family physician/medical anthropologist (WV) and the other a veteran medical sociologist/medical educator (RF)—plus a growing literature that speaks to the importance of the BPS approach and its successors on quality of care, (29) overall outcomes (24–26), and interpersonal satisfaction (30).

We frame our considerations in two opposing directions: first, as add-ons to the BPS approach—ways to expand our appreciation of patient-oriented concerns; and, second, as add-ins—ways to appreciate the approach as a means of influencing our own cognitive habits and practice behaviors. The purpose of this article, thus, is to help generalist practitioners personalize their use of the BPS approach so as to help nurture their therapeutic presence with patients and, ultimately, positively influence patients' health.

## ADDING-ON TO THE BPS APPROACH

The traditional BPS approach refers to a natural system hierarchy in which patients are located somewhere on a continuum between subatomic particles and the biosphere (1, 2). The BPS approach suggests clinicians focus on the level of patients as people first, simultaneously appreciating how other system constituent themes influence patients' experience of disease and illness. From a thematic perspective, the traditional approach

focuses, self-evidently, on the biological, psychological, and social dimensions of patients' lives.

Over the years, clinicians and scholars have added-on several other themes to the original approach. Some years ago, “spiritual” became a common appendage in generalist literature, giving recognition to the influence of religion and spirituality on the health and well-being of human beings (31, 32). As well, cultural and political-economical themes of care emerged as early generalist add-ons (5, 33). Much more recently, a number of other add-ons have come to the fore from outside of generalist circles—examples include such auxiliary themes as history, microhistory, and intersectionality (from psychiatry) (34, 35), social changeways and dynamic microsystems (from psychology) (36, 37), and institutional influences (from physiotherapy) (38).

Our personal favorite thematic add-ons, broad in scope echoing our generalist backgrounds, are ecological and existential in nature. We do not, however, recommend anyone use the term “BioPsychoEcoSocialExistential.” It is a quite a mouthful and, simply, another artificial construct with extra perceptual boundaries to contend with. We prefer generalists keep things simple—BioPsychoSocial is perfectly suitable in this regard (Table 1).

In addition, add-ons can take the form of specific structural factors that affect the milieu in and the process by which practitioners interpret the BPS approach (Figure 1). Differences in these factors invariably alter how individual practitioners implement the approach. These specific factors reflect the location and setting of care, the nature of any particular patient's concerns, and the characteristics of the practitioner's professional background (53). Drawing from literature that speaks to the nature of generalist practice—specifically, that generalists are likely to see patients across the lifespan in short visits over long periods of time; attend to concerns both acute and chronic; strategize care that simultaneously bridges prevention, management, and cure; and address multiple undifferentiated problems across a range of concerns (54)—we suggest four structural factors are key: context, continuity, intentions, and externalities (Table 2).

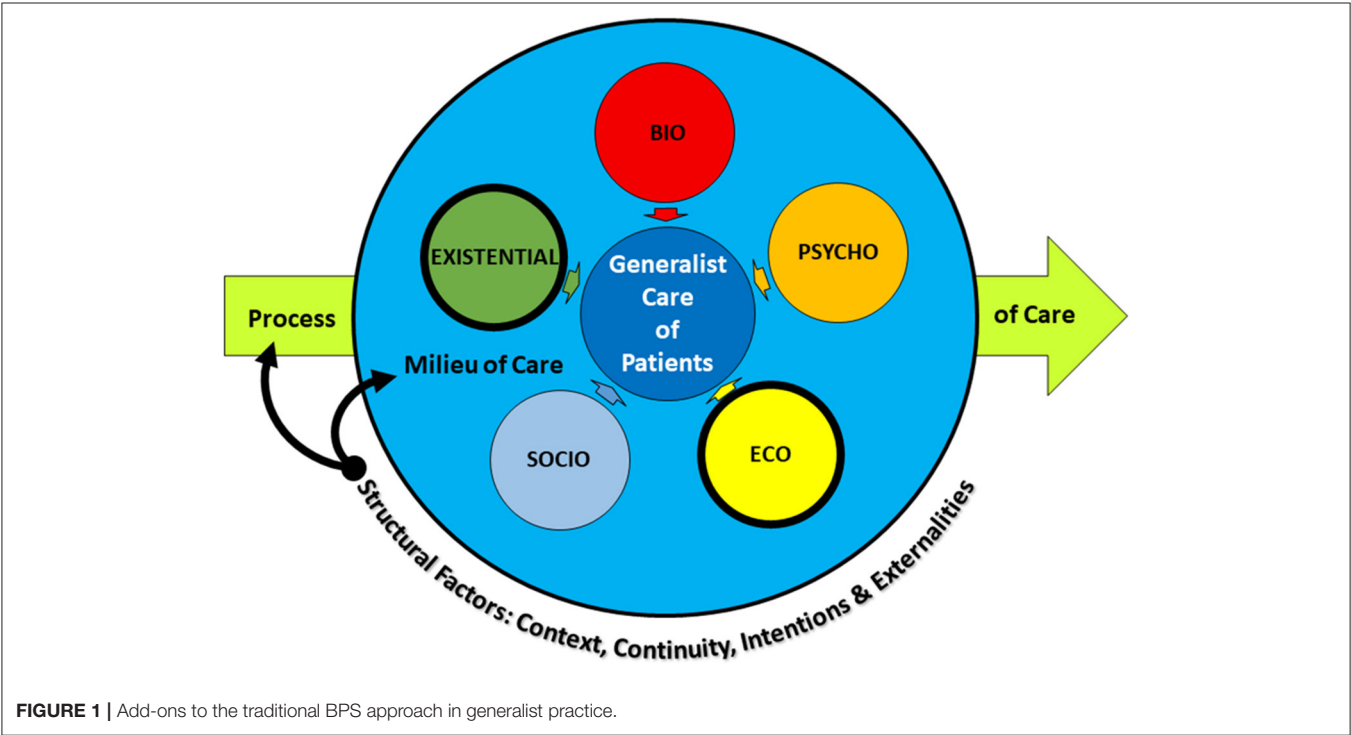
## ADDING-IN TO THE BPS APPROACH

The BPS approach initially focused on individual patients embedded in complex bureaucratic systems. We agree this perspective is important. We also suggest that generalist practitioners develop the ability to see themselves as integral parts of these systems. We encourage them to appreciate their use of the BPS approach with patients as a means of identifying add-ins—organically produced insights that arise in the course of patient encounters—in order to critically consider how to do the best they can, in any moment at hand, given the circumstances of any clinical situation, and help patients move toward health.

Given the current culture of medicine that marginalizes the holistic practice of generalist medicine, attending to these tasks may not be easy. We suggest, however, the BPS approach is bi-directional, and that by applying it with patients in everyday practice generalists can develop their professional identities as

TABLE 1 | BioPsychoSocial add-ons: ecological and existential themes.

Theme	Rationale
Ecological	The ecological theme is informed by the environments in which people live and the influence these environments exert on individual and collective health and well-being. Ecological considerations are myriad and affect spaces large and small. On a macro scale, they include such factors as the effects on health and well-being of natural and built environments (39); the significance of both geographic community of origin and the effects of local, regional, and global migration (40); the distinct influences of rural, suburban, and urban living (41); and the looming burden of climate change (42). The appearance of COVID-19 as a global pandemic, the emergence of the Me Too and Black Lives Matter movements, and the end of the US occupation of Afghanistan are three recent events that have already and will likely further change the macro-ecological dimensions of lived environments around the world. An example of the ecological dimension on a micro scale is the migration of the Electronic Medical Record from the back room to the examination room or hospital suite (43). Although documenting while doctoring has transformed medicine in many advantageous ways (e.g., medication reconciliation, order entry, and access to internet resources), it has also posed significant challenges (44). By splitting attention between the computer and the patient, it has triggered unintended consequences that often lead to “distracted doctoring” (45, 46). In addition, taking ecological influences on health into account can be as simple as acknowledging where patients present: in an ambulatory clinic, community hospital emergency department, or academic medical center (47).
Existential	The existential dimension of the BPS approach focuses attention how patients make meaning in the face of disease and illness and how practitioners reciprocally bear witness to and experience their patients’ suffering (48, 49). There is clearly a spiritual aspect to these dimensions, as some scholars have already noted and named as the “BioPsychoSocialSpiritual” model (31, 32). Meaning, however, transcends spirituality (50). Work, relationships, community, education, awareness, and ethical considerations are also sources of meaning for patients, whether practiced as behaviors, habits of mind, or soulful ways of being. So, too, are instances of intersubjective awareness, moments of “connection” when doctors and patients harmoniously recognize and acknowledge each other’s humanity at a very basic level (51). From the perspective of traditional practice, in which generalists routinely meet their patients and those who accompany them in clinic examination rooms or hospital suites, these moments play key roles in establishing a shared presence that is therapeutic in and of itself (52).



caring and humanistic healers. They can come to understand how clinical encounters are coproduced (69), examine how practitioners’ own implicit biases influence the provision of care as well as the healing process (70), and consider how personal histories and professional socializations affect the processes and outcomes of care (71). Additionally, they can appreciate how to employ cultural sensitivity (72), with cultural humility (73), relative to patients and their concerns and as influenced by where they practice and the resources available. They can learn how to

recognize, investigate, and manage the feelings and thoughts that are integral to enhancing practitioner equanimity in the face of anxiety and contentment in the face of stress.

Adding-in the BPS approach, with the aim of strategically cultivating professional growth, calls for generalist practitioners to use other key principles of practice [including such longstanding principles as affinity, intimacy, curiosity, and fidelity (74)] in the moral and ethical milieu that exists between them and their patients (75). It encourages them to nurture



**TABLE 2 |** BioPsychoSocial add-ons: structural factors.

Factors	Rationale
Context	Context is the medium in and through which all relationships exist, be they professional (as between a practitioner and patient) or personal (as in activities of daily life). Appreciating the social, cultural, and emotional influences of context on clinical encounters is helpful when assessing how patients (and, reciprocally, practitioners themselves) make sense of disease and illness. Contextual factors can be as simple as asking a patient trying to quit smoking about other tobacco users in the household. Alternatively, they can be as complex as trying to appreciate how Adverse Childhood Experiences (ACEs) or Adverse Shared Historical Experiences (ASHEs) influence patients' presentations and practitioners' responses (55, 56). As in the case of the current COVID-19 pandemic, contextual factors can also arise up without much warning and trigger physical, emotional, and relational distress around the globe.
Continuity	Interactions between practitioners and patients often evolve over a lifetime. It is common for patients in generalist practices to see the same practitioner over the course of several encounters for concerns of varying clinical intensity. Continuity of relationship allows for the evaluation, diagnosis, and management of emerging concerns in light of the natural history of diseases and individual differences in their expression (57). Evidence shows that continuity of care and relationships lead to better patient experience and improved health outcomes (58). Continuity also positively influences practitioners' attitudes toward their work. Multiple studies document that the most meaningful aspect of doctoring is developing and maintaining interpersonal relationships (59).
Intentions	The elements of therapeutic communication—including, but not limited to, active listening (60), the demonstration of empathy (61), and a probe-and-pause question-oriented approach (62)—are habits of practice that contribute to improved patient outcomes (63). So are intentions of practice: the thoughtful consideration of how to develop and employ one's self-awareness and relational acumen as a practitioner (64). Specifically, the BPS approach neither starts nor stops at the exact moment an exam room door opens or closes; its use is conditioned by practitioners' attention to the iterative steps of recognition, engagement, reflection, action, and review in their therapeutic interactions (65), the ongoing, in-the-moment process of being with patients in clinical encounters.
Externalities	Externalities are commonly encountered factors outside the practitioners and patients' control that shape their interactions. They include reimbursement schemes that preferentially reward throughput over humanistic care (66); in-room electronic medical record systems that divert attention from direct care of the patient (67); and educational systems that prioritize narrowly biomedical models of diagnosis and treatment to the exclusion of social and emotional determinants of care (68). Absent acknowledgment, consideration, and action, in the face of such externalities care may become overly transactional and symptom focused, leading to poorer overall outcomes for patients and reduced job satisfaction for practitioners.

attributes such as emotional intelligence (76), adaptive expertise (77), and clinical courage as instruments of therapeutic change (78). It also encourages generalists to engage in the communities they serve (79), to use and cultivate an anthropological gaze as to the world around them (80), and to see their role as a call to action for social accountability (81). The BPS approach, in this way, is an expression of the interconnected nature not only of the doctor-patient relationship, but also a guide for generalists to become more adept—clinically wise—on their professional path from competency to capability to capacity and beyond (82).

Generalists (and, indeed, specialists, subspecialists, and other health care professionals) can consciously develop their clinical wisdom by attending to add-ins as personalized insights into growing their professional identities (83). This growth emerges from thinking about thinking (metacognition) (84), feeling (values education) (85), and doing (experiential learning) (86). In turn, such reflective thinking can help generalists enhance their cognitive abilities, expand their affective awareness, and develop their performative proficiencies (Figure 2).

### CLINICAL CASE STUDY

We present a brief clinical case study to illustrate how add-ons and add-ins are intermingled with the process of applying a BPS approach in clinical encounters (Table 3). For demonstration purposes only, we list both add-on themes and factors and add-in insights separately and sequentially; the reality is that the BPS approach and the themes, factors, and insights we enumerate are more dynamic than static and more systemic than linear

in nature. As many generalists have previously noted, using this kind of approach is a “way of being” in practice that is incorporates practitioner awareness, patient- and relationship-centeredness, in-the-moment flexibility, integrated teamwork, and shared presence as regularly practiced habits (11).

### DISCUSSION

The point of introducing these considerations is to suggest that generalist practitioners consider the BPS approach not as a model set in stone, but as (1) an inspiration for further integrating BPS concepts into practice, (2) a stimulus to promote patient- and relationship- centered approaches to patient care, and (3) a means to of repositioning themselves in the space between patients' lived experience and the culture of medicine (87). The BPS approach offers generalists not only a broad understanding of the many factors that contribute to the evaluation, diagnosis, and management of presenting problems, but also a path to reconceptualize professional growth in service of therapeutic agency (one's ability to affect positive change) and well-being on both sides of the stethoscope.

More important, the point is that generalist practitioners consider the BPS approach as a template for exploring their own contributions to the healing process by examining not only their roles and relationships vis-à-vis the patients they serve, but also the attributes of clinical wisdom they develop and express along the course of their professional lives. The add-ons and add-ins we suggest can and should be modified



**FIGURE 2 |** Developing clinical wisdom—dimensions of personal growth. \*We list examples in these categories for illustrative purposes only; they are not all-inclusive in nature.

or supplemented by others considerations, as appropriate—the overriding goal is doing the right thing at the right time, under the circumstances at hand, for the betterment of patients’ health and with the intent of improving their well-being. The BPS approach in this way can help generalists envision, create, and incorporate original add-ons and add-ins to enrich their healing talents.

In fact, we encourage generalist practitioners to take personal ownership of the BPS approach and apply it, distinctively, with all patients in their daily work. We hope they use the approach as a directional marker pointing the way toward individual clinical excellence in holistic patient care. Collectively, we hope they and their colleagues in other disciplines use it as guide to making the practice of generalist medicine and medicine as a whole more inclusive, humane, efficacious, and satisfying. Given current circumstances, external incentives tying compensation to patient experience may be helpful in nudging these aspirations along (88).

These aspirations are particularly fitting as means of countering the increasingly fragmented, hyper-technical, production-oriented, industrialized model of medical practice that exists at this very moment in time, especially in the United States. The BPS approach may also help remediate traditional medicine’s acknowledged failures in the face of injustice, inequity, and political polarization, forces that increasingly appear to negate not only the ultimate effectiveness of medicine, but also the healing satisfaction characteristic of its practice.

## FURTHER THOUGHTS

First, we are fully aware, and have noted above, that the BPS approach is applicable beyond generalist medicine. The approach has utility in specialty and subspecialty medical practice as well as in a variety of other health care disciplines, and literature emergent from those disciplines has enlightened our own understandings of the BPS approach. Our purpose in focusing on generalist practice is not to exclude others who attend to patients. It emerges, however, from our assessment that the BPS approach is central to the everyday practice of generalist medicine: with the exception of those patients who present with imminently life threatening conditions, the BPS approach is applicable, to greater or lesser degree, at all times in all situations with all patients who present to generalist practitioners. Due to the nature of clinical interactions in specialty and subspecialty care, the BPS approach is generally—and appropriately—a supplement to the biomedical model, invoked either in response to certain presenting problems or when the traditional linear course of diagnoses and treatment has been tried and failed.

Second, any approach to understanding the complexity of human life in relationship to the very real experience of disease, illness, and sickness will inherently find itself limited by the words used to describe it. This is especially true when considered independently of the context of a particular patient’s individual history, current experience, or the circumstances under which individuals turn to the medical care system in times of need. No textual explanation or graphic representation can wholly

**TABLE 3 |** Clinical case study—patient presentation, add-ons, and add-ins\*.

Patient presentation <sup>†</sup>	Add-Ons <sup>‡</sup>	Add-Ins <sup>§</sup>
The patient is a 63-year-old male who presents with several years of headaches, dizziness, and unsteadiness. He recently arrived in the U.S. as a religious refugee from Moldova. His wife accompanies him; a Russian-speaking interpreter translates.	Biological Ecological Context	Thinking: Reflection
He notes he is ashamed by his unsteadiness—in his rural community of origin, he was considered the town drunk. “Only I don’t drink”, he notes. “I am a Christian. My children are now here, in the U.S. I want them to know I am a good father.”	Psychological Existential Social	Feeling: Empathy
The patient’s blood pressure is 240/140, his pulse 100. I then “talk” him through his exam. His heart sounds are regular with a normal S1 and S2. His lung fields are clear. He has trace lower extremity edema. He is alert and oriented. His neurological exam is non-focal.	Biological	Doing: Communication
I ask if he has ever heard of high blood pressure; he has not. I explain how his blood pressure might be the sole cause of his symptoms. I explain I will order some lab tests, get a tracing of his heart (EKG), and suggest some pills for him to take daily. I note my medical assistant and I will see him, in short visits, frequently, over the course a month and regularly thereafter. I inquire, “How does this sound to you?” I ask his wife, “Are you, too, comfortable with this plan? Do you have other concerns that we haven’t addressed?”	Biological Biological Social Externality Ecological Intention	Thinking: Critical Reasoning Doing: Education  Feeling: Engagement Doing: Inviting Presence
I request the interpreter investigate what the patient and his wife have understood and leave the room to see another patient. I return after labs are drawn and an EKG done to prescribe a standard antihypertensive medication.	Externality Biological	
At a visit six month later, the patient’s blood pressure controlled with multiple medications and his dizziness and unsteadiness fully resolved, the patient—very appreciative for the care we have provided—asks, “now that I am cured, can I stop my pills?”	Continuity Biological Psychological Existential	Feeling: Equanimity Thinking: Creativity

For case purposes: add-ons/add-ins summarized as discrete/disconnected/identifiable  
In practical application: factors are a “way of being”—systemic/dynamic/interconnected

\*This clinical case presentation summarizes actual interactions that occurred in Dr. Ventres’ community-based practice.

<sup>†</sup>For a more detailed review of this case study, please see Ventres (62).

<sup>‡</sup>We note only add-ons mentioned in the text (Tables 1, 2). We encourage practitioners to use these as a starting point for further personalizing the BPS approach.

<sup>§</sup>We use a thinking, feeling, and doing model to frame add-ins to the BPS approach. Other learning processes could function as alternative methods of self-growth, including the questioning list noted in Ventres (62).

represent the dynamic process of clinical encounters (36), just as no single recommendation for enhancing such encounters is applicable or appropriate in each and every setting. The reality is that the BPS approach, with or without add-ons or add-ins, can only approximate some of what goes on between practitioners and patients (89), let alone what goes on in the consciousness of individual patients or practitioners beyond the veil of clinical presentations.

Third, another reality is that interactions between practitioners and patients do not always go as planned or go well. No conceptual approach or practiced skill can guarantee perfection in all clinical encounters, especially in light of the many influences that shape them. While challenging to endure, conflicts and mistakes can provide generalist practitioners with opportunities to learn and incorporate new knowledge, new patterns of thought, and new expressions of care in their work with patients. Often it is not what one does, but what one does next that counts—communication strategies such as conversational repair and apology can be taught, learned,

and put into practice, benefitting patients, practitioners, and the therapeutic relationships that exist between them (90, 91).

## CONCLUSION

The BPS approach has been a part of the practice and teaching of generalist medicine since its introduction over fifty years ago. It provides an important foundation for considering, conducting, observing, reflecting upon, and providing feedback about the intricacies of clinical care, healing interactions, and practitioner-patient communication. It has, however, struggled to gain broad acceptance in the face of a dominant linear model of biomedical practice. Given new developments in the practice of generalist medicine and the world as we know it, we suggest that generalist practitioners view the BPS approach and its offspring, Patient- and Relationship-Centered Care, as dynamic and modifiable templates in service of both addressing patient concerns and improving their own clinical awareness. We offer for reflection ways to add-on to the BPS approach

several thematic considerations and structural factors in order to further develop its efficacy with patients. We also suggest how generalists can use the BPS approach as an add-in to enhance self-awareness and understand their own signature presence as healing professionals. We encourage generalist practitioners to view the BPS approach as an invitation to explore ways to improve patients' health and well-being as well as their own joy and resilience in the practice of medicine.

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# “Whose Fault Is It?” How Rural Chinese Women Explain Intimate Partner Violence: A Qualitative Study

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Women are often the victims of intimate partner violence (IPV). Though China has established its first statute against domestic violence, the service developments for victims fall behind. It is important to assess community members' perceptions of what causes IPV to create interventions to prevent and address IPV. This study completed the Short Explanatory Model Interview (SEMI) among a subset sample from a large epidemiology study in rural Sichuan China. The social ecological model was applied to analyze qualitative interviews. Among 339 participants, the average age was  $46.01 \pm 12.42$  years old. There were 31.86% of them had been educated, 14.75% of them had migrant worker partners, and 49.26% of them had experienced violence from their partners in the last year. There were 252 participants attributed IPV to individual factors, and they primarily discussed the social characteristics, behaviors, personalities or even health problems of the husband or the wife in the vignette. Under this theme, there were 86 participants blaming the victim for being anxious, social disconnectedness or lazy; and there were 166 participants blaming to the perpetrator being abusive, irresponsibility, lack of understanding, and cheating. There were 44 women believed the cause was relational, in which there were 41 participants attributed the problem to the broken relationship between the couple and three participants attributed to the lack of support. There were 28 participants believed the cause was communal and societal, such as being poor, family problems, fate, and believed IPV was a common scene. There were 15 participants could not identify the cause of IPV. These participants usually provided very brief responses and barely had insight on violent behaviors or confidence in discussing the cause. Our findings offer a direction for understanding the rural Chinese women's beliefs about the etiology of IPV to better develop interventions which must consider raising a public awareness campaign about the risk factors of IPV and focus on reducing self-blame among victims.

**Keywords:** intimate partner violence (IPV), explanatory model, women's voices, rural China, social ecological model (SEM)

## INTRODUCTION

This study of intimate partner violence (IPV) in China occurs against an international backdrop of service developments for victims during the past half-century. IPV against women—a form of gender-based violence committed by a person who has a close personal relationship (typically, spousal or partner)—includes acts or threats of violence that result in harm or potential harm that is physical, sexual, or mental (1). According to the WHO (2), the lifetime prevalence of this major public health problem ranges from 13 to 61% globally for women; despite being a fundamental violation of human rights, it often has been ignored internationally despite decades of calls for greater recognition of the health and social needs of women.

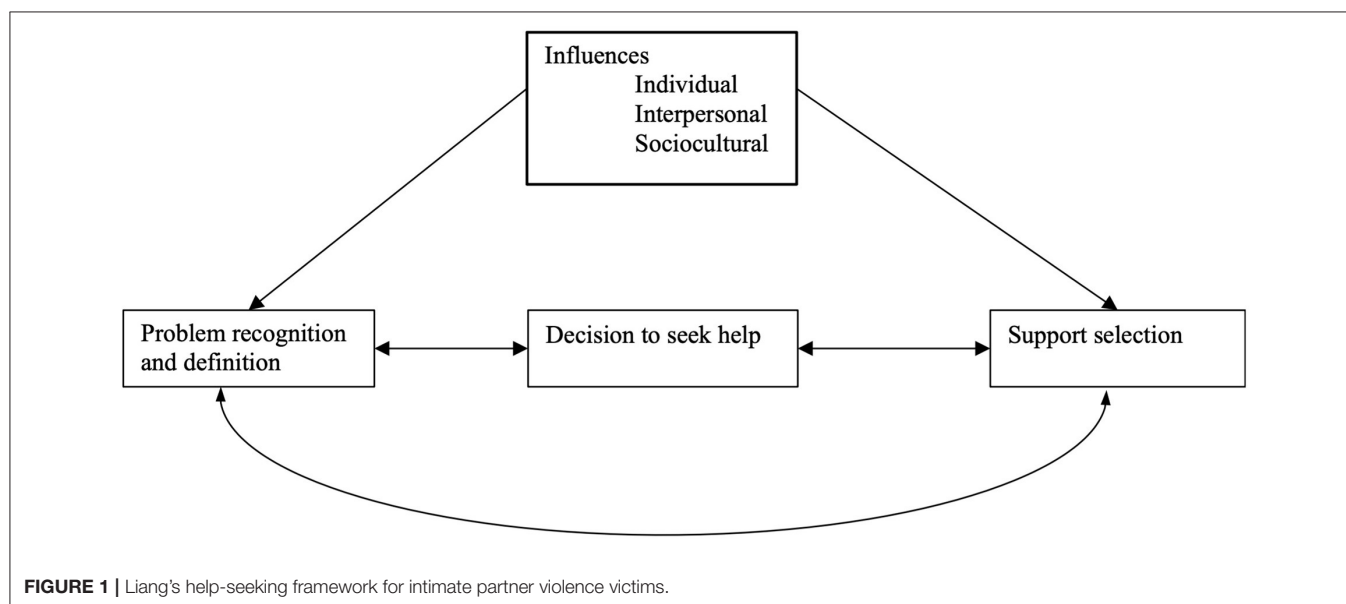
It is in this context that some countries have taken the lead to develop needed resources for victims (3). During the 1970s, we saw the emergence of shelters and hotlines (4). In the ensuing years, programs offering social support and court advocacy developed (5, 6). In some nations, current services range from shelters to ongoing support, including provision of physical and mental health services (7). Recently, there have been initiatives to create medicine-law partnerships that offer coordinated, comprehensive services for victims at a single site, including the emergence of Family Justice Centers (8). However, despite all these services, many victims never seek help for myriad reasons. Liang et al. provided a theoretical framework to explain how victims make help-seeking decisions in the midst of their chaotic lives, and they suggested that individual, interpersonal, and community level variables influence help-seeking behaviors (**Figure 1**) (9). Additionally, abusive partners may control their victims in many ways that can interfere with help-seeking. Efforts to sabotage help-seeking can include threats and intimidation, forced coercion, and alternatively, promises to improve behavior and pledges of love and commitment. Liang et al. underscored

that, while services may exist, survivors of abuse may not know how to seek them, in addition to fearing the repercussions from their partner if they do. Additionally, asking for help by reaching outside one's family may not be consistent with long-held cultural beliefs of perceived norms.

There have been relatively few studies of IPV in China, and these largely have been cross-sectional surveys designed to report the prevalence of IPV. In urban areas, Xu reported the incidence of physical violence ranged from 6 to 14% across age groups (10). Guo et al. reported that the lifetime prevalence of any IPV was 11.7% among pregnant women, aged 19–45 years (11). Another study among young women seeking abortions in hospitals found a lifetime prevalence of 22.6% (12).

Studies from rural areas typically found higher lifetime prevalence rates. These ranged from 19 to 29.7% for women suffering physical violence (13–15). Studies found prevalence as high as 58.1% among women suffering lifetime psychological violence and 16.7% for those experiencing lifetime sexual violence (14, 15). Other studies of IPV in China focused on exploring women's knowledge and attitudes of IPV with quantitative surveys. For example, 82.0 to 94.1% of urban residents identified physical violence such as hitting, kicking, and attacking with a weapon, yet only 16.1 to 20.8% recognized teasing, cursing, or deliberate silence between partners as potentially abusive behaviors (16). Further, it was also reported that women would justify violence for causes such as disobedience to parents-in-law, refusing to have sex with one's husband, and having affairs (17).

It is likely that traditional Confucian culture may have an especially strong influence on women living in rural Chinese communities who experience IPV, where residents are less likely to experience Western culture influences. Consequently, rural Chinese women may believe they are inferior, in turn diminishing help-seeking. A study involving married female migrant workers,





most of whom came from rural China, reported that 11.1% agreed that a husband could beat his wife when she showed no or little filial respect for parents-in-law, and 15.7% agreed a husband could beat his wife when she had another sexual partner (17). Some Chinese cultural beliefs do not encourage victims to seek help from others; e.g., the traditional Chinese value “*jia chou bu ke wai yang*” (“domestic shame should not be made public”) may stop rural Chinese victims from seeking help due to shame and stigma. Further, as a “high context culture” that values indirect communications that are interpreted contextually, individuals may repress expressions of personal need, of “self,” to avoid conflicts and achieve harmony (18).

The purpose of this study was to qualitatively study rural Chinese women’s perspectives on what causes IPV in the context of their lived experiences. To discern the perspectives of our rural participants, we used a mixed-method semi-structured interview to begin to piece together how a social ecological model (SEM) might inform future interventions.

## METHODS

### Sample and Sampling

We drew our sample from a larger epidemiological study that assessed mental health problems and associated factors among rural women of Guangyuan City (19, 20). Guangyuan City was one of the most economically underdeveloped regions in Sichuan province (21). With the assistance of local health providers, the parent study used multi-stage sampling to recruit a random socio-economically diverse sample of 13 villages. To be included, women needed to be 16 years of age and older (16 is the age of consent in China), to have been living locally for at least 2 years, and to have reported they were married or in a relationship in the preceding year. Potential participants who carried a diagnosis of a major psychiatric disorder (e.g., schizophrenia and intellectual disability), based on registration lists provided by local hospitals, were excluded. All study participants provided oral consent.

The qualitative study explores the phenomena of IPV, and we applied probabilistic sampling to include every fifth woman who reported they were married or in a relationship in the preceding year from the parent study’s sample (22). We compensated participants for their time with toiletry items (such as toothpaste and soap) worth 5 yuan (about 0.8 USD).

### Ethical Statement

The Ethics Committee of Sichuan University reviewed and approved the protocol, including the verbal informed consent process. The University of Rochester Research Subjects Review Board reviewed the approval from Sichuan University and approved analyses of de-identified data. Local health authorities from Guangyuan City assisted with the overall implementation of the study, and local health providers aided recruitment of participants.

## Measures

### Demographic Information Questionnaire

We collected sociodemographic information including age, education, occupation, family structure including nuclear family

(a pair of adults living with their children), stem family (the grandparents, their married children, and grandchildren who live together under the authority of the grandparents), joint/expanded family (more than two related nuclear and/or stem families living in a single household), partner’s occupational status (migrant work or not), and family annual income.

## SHORT FORM OF THE REVISED CONFLICT TACTICS SCALE

We used the Short Form of the Revised Conflict Tactics Scale (CTS2S) to assess participants’ current violence experiences, which has been widely applied globally (23–25); the Chinese version was translated in Hong Kong and has been applied in the Mainland with good reliability and validity (26–28). It contains statements about IPV experiences, and each statement examines the frequencies of IPV experiences from “zero” to “more than 20 times” during the past 12 months. We administered six victimization statements across three domains of IPV and coded any of the endorsed statements as a positive screen for IPV. Cronbach’s  $\alpha$  was 0.85 for this study sample.

## SHORT EXPLANATORY MODEL INTERVIEW

To assess participants’ explanatory models (EMs) of IPV, we applied the Short Explanatory Model Interview (SEMI), a brief validated assessment based on the EMs (29–31). The EMs are how people understand diseases, relate meaning to symptoms, explore the causalities, and express their expectations of treatment and related outcomes, which are culturally determined.

The SEMI explores details related to EMs of disease and helps researchers understand the perceived cause of the condition, the timing and mode of onset of the symptoms, the perceived pathophysiological processes involved, the beliefs about the natural history and severity of the condition, and the appropriate treatments for the condition. There are six sections (Health & Illness, Perceived Severity, Expectation & Satisfaction, Activities & Functioning, Other Health Behaviors, and Vignettes), and each section consists of a series of open-ended questions and probes in plain language without any professional medical terms. The SEMI encourages participants to provide answers based on their own experiences, attitudes, and beliefs to explore the relationship among research questions, social/natural circumstances, and social/cultural circumstances.

This study focused on the vignette section of the SEMI. Vignettes are brief narratives about hypothetical situations that are often used in qualitative research to elicit information about how a respondent thinks about a situation. They are particularly helpful for eliciting information about sensitive topics that respondents might not feel comfortable discussing about themselves (32). The vignette used was developed to depict an IPV situation in rural China (see below); we read the vignette to participants and then asked them to respond to open-ended questions related to the EM. An interdisciplinary team wrote the vignette: a psychiatric doctor, a primary care physician, and

an attorney with IPV intervention experience, in partnership with two epidemiologists with rich epidemiological research experience in rural China.

*There is a woman, 35 years old and doing agriculture work. Her husband is a migrant worker in a city far away and barely comes home. Recently, her husband returned home from the city for a visit, but he kept yelling at her, calling her names. He said she embarrassed him in front of his friends because she wasn't well educated. Now, he barely talks to her at home, and he beats her when he is drunk or loses money after gambling. Every morning, compared to getting up and then doing work, she prefers to stay in bed and cover herself under the comforter. She feels so lonely, and she misses her family very much.*

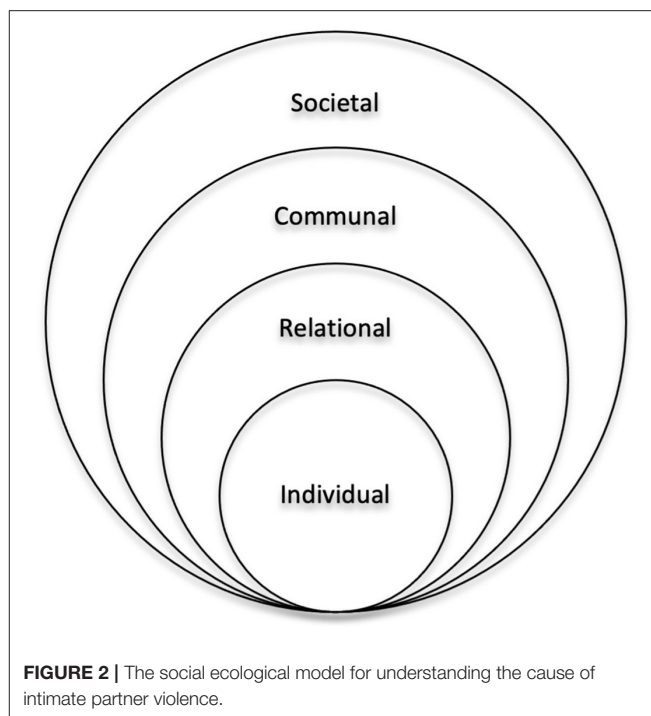
*Question: What are the causes of her problem?*

## Data Collection and Quality Control

In July 2012, we conducted the interviews with recruitment help from the local government and Guangyuan Mental Health Center as coordinators. We implemented strategies to increase the trustworthiness of the study. First, coordinators contacted village leaders and village doctors and held public information sessions about the study in villages before the survey began. Second, during the field survey, village leaders, doctors, and seniors escorted study interviewers door-to-door to conduct surveys for the larger study to increase participants' trust in this study; as some villages have low population density, local residents helped interviewers by transporting them with motorcycles. Third, considering IPV as a sensitive topic, we conducted the qualitative interview after participants completed the quantitative questionnaire for the larger study; and we conducted the interviews in private settings without any disturbance from participants' family members, neighbors, and friends. Interviewers recorded participants' responses to questions. We also randomly audio-recorded 46 interviews after participants' oral consent at the beginning of the field survey for quality control. Fourth, to reduce misunderstandings during interviews, we recruited graduated students who could speak and understand the local dialect in Guangyuan City as interviewers. The interviewers completed training sessions related to semi-structured interview methods and skills. There were three research teams, and each team had eight interviewers led by experienced senior researchers. We required all interviewers to check for missing items in the questionnaire after each interview, and they would complete missing items before leaving the household. Senior researchers reviewed recorded interviews, discussed encountered challenges and difficulties, developed strategies to improve interviewers' skills, and conducted quality control meetings to address issues.

## Coding and Analysis

International studies reveal common risk factors of IPV, and a helpful lens to view these risk factors/causes is the social ecological model (SEM) (33, 34). According to the model, IPV results from the interactions of associated factors that are embedded at individual, relational, communal, and societal levels



and the overlapping rings in the model illustrate how factors at one level can influence factors at another level (**Figure 2**).

We applied the SEM to explore and understand rural women's explanations of IPV (33). Because this was a heavily scripted interview with a vignette prompt, we did not use the grounded theory. Rather, we read through all responses, selected the SEM as a framework, and utilized this approach (35). Thus, we could avoid coding data that were heavily influenced by the interview prompts. There were four coders who independently coded the qualitative data into categorical and numerical codes based on the SEM. If their codes were different for the same passage, the team would discuss the discrepancy until reaching consensus. After coding, we entered the categorical and numerical data into a database for content analysis.

## RESULTS

We selected a sample size of 379 participants out of 1,898 participants from the larger study, and 339 of them (89.45%) completed the semi-structured interview.

Participants were 19 to 81 years old with 57.23% (194/339) between 40 and 59 years old, and the mean age was 46.01 years (SD: 12.42); 99.71% (338/339) were of Han ethnicity (Han is the dominant ethnic group in China); 31.86% (108/339) had never been educated, and 44.25% (150/339) had received <6 years of education (primary school); 50.44% (171/339) were living in a stem family; 14.75% (50/339) had migrant worker partners. Of participants' family annual income, 28.32% (96/339) and 23.00% (78/339) ranged from 10,000 to 19,999 yuan and 20,000 to 29,999 Yuan, respectively;

**TABLE 1 |** Participants' characteristics and IPV experiences ( $N = 339$ ).

Demographic information		Any IPV experience		Frequency	Proportion (%)
		No	Yes		
Age (years old)	19–29	26	19	45	13.27
	30–39	30	23	53	15.63
	40–49	49	62	111	32.74
	50–59	43	40	83	24.48
	60 and above	24	23	47	13.86
Ethnicity	Han	171	167	338	99.71%
	Others	1	0	1	0.29%
Education	No school	58	50	108	31.86
	Less than 6 years	73	77	150	44.25
	More than 7 years	41	40	81	13.89
Family type	Living along/with friends	4	5	9	2.65
	Nuclear family	70	70	140	41.30
	Stem family	85	86	171	50.44
	Extended family	13	6	19	5.60
Husband as migrant worker	No	144	136	280	82.60
	Yes	24	26	50	14.75
	Unmarried	3	4	7	2.06
Annual family income (Yuan)	0–9,999	29	34	63	18.59
	10,000–19,999	47	49	96	28.32
	20,000–29,999	40	38	78	23.01
	30,000–39,999	23	16	39	11.50
	40,000–49,999	15	13	28	8.26
	50,000 and above	18	17	35	10.32
Total		172	167	339	

of note, in 2012, the low, lower-middle, middle, upper-middle, and high-income households in rural Sichuan were defined as per capita annual income under 3,074, under 4,950, 6,709, 8,905 and 14,428 Yuan (36) (see **Table 1** for details).

Overall, 49.26% (167/339) of participants had experienced violence from their partners in the last 12 months. The rate of physical, psychological, and sexual violence was 25.07% (85/338), 46.61% (158/339), and 7.08% (24/339), respectively.

## Explanations of Intimate Partner Violence

Overall, the participants' responses to the vignette question "What are the causes of her problem?" fell into four main themes related to their perceptions of the cause of IPV in the vignette: individual factors ( $n = 225$ ), relational factors ( $n = 44$ ), communal and societal factors ( $n = 15$ ), and unidentified ( $n = 15$ ). We briefly presented these themes in **Table 2** and describe them below.

## INDIVIDUAL FACTORS

The majority of the responses ( $n = 225$ ) fell into a theme we termed "individual factors," which suggested participants attributed the conflicts in the vignette to either the woman or the man. We created profiles for the descriptions of the women

**TABLE 2 |** The causes of IPV in the vignette explained by participants ( $N = 339$ ).

Causes of IPV	N	Examples of answers
Individual factors	225	<ul style="list-style-type: none"> <li>• "I think the cause is she has too much pressure."</li> <li>• "It is because everything goes against her, and she has pressure."</li> <li>• "Her husband works hard for the family, she doesn't care about him, of course he is angry."</li> <li>• "She doesn't do housework at all, that's how she pisses her husband off."</li> <li>• "He drinks, gambles and beats her."</li> </ul>
Relational factors	44	<ul style="list-style-type: none"> <li>• "They have problems in communicating with each other."</li> <li>• "They have been separated too long, and the relationship goes down."</li> <li>• "...either one of them cheated the other..."</li> </ul>
Communal and societal factors	15	<ul style="list-style-type: none"> <li>• "Her family doesn't have much money, they are poor."</li> <li>• "Financial issues I guess, her family doesn't have much money to live well, nor does her."</li> <li>• "The family financial problem makes them suspicious to each other."</li> <li>• "It's her fate, she doesn't have a good husband, and she can't have a good life in the future."</li> </ul>
Unidentified	15	<ul style="list-style-type: none"> <li>• "I don't know."</li> <li>• "It's all about the young generation, I'm old and don't know about these things for a whole life."</li> </ul>

that fell into this theme. Please see **Table 3** for an example. These participants primarily discussed the social characteristics, behaviors, personalities, or even health problems of the husband or the wife in the vignette.

Over one-third of participants ( $n = 86$ ) described the cause as the woman was "anxious," "social disconnectedness," "lazy," or "introvert," which we interpreted as victim blaming. A common term merged in this theme: mental problems. This umbrella term referred to a series of psychological or psychiatric problems. For example, "She has few contacts with the outside world, and her husband has left for a long time. "So she has some kind of anxiety," and "Her unhappiness is in the Sixiang (which can be roughly translated as mind or thoughts)," and even "She is looking for death." At other times, the participants associated the conflict with the woman's characteristics or skills. One participant stated, "She has never been educated in school, and she can't do things like other educated people can. No wonder her husband is mad at her," while another said, "She doesn't do housework at all, that's how she pisses off her husband."

The remaining participants in this category ( $n = 166$ ) attributed blame to the husband and described the cause of the man as "torturing," "being irresponsible," "verbal abuse," "lack of understanding," "despise," "cheating," and "disappointment," which we interpreted as perpetrator blaming. A common theme that surfaced among responses was irresponsibility. For example, "If she has already taken care of him so much and he still acts like this, his problem, he shouldn't (do this to her)," and "...he doesn't care about her at all." Some participants directly recognized violence or pointed out the term "domestic violence" in simple responses, such as "He tortures her" and "It's domestic violence." There were also participants who associated the conflict to

**TABLE 3 |** The causes of IPV at individual level explained by participants.

Individual causes	N	Subcategory of factors	Examples of answers
Victim blaming	45	Mental problems	<ul style="list-style-type: none"> <li>• “I think the cause is she has too much pressure.”</li> <li>• “Her unhappiness is in the Sixiang (mind or thoughts).”</li> <li>• “It is because everything goes against her, and she has pressure.”</li> <li>• “She is in a bad mood and hasn’t been relieved from the feelings yet.”</li> <li>• “She has few contacts with the outside world, plus her husband has left for a long time, she has some kind of anxiety.”</li> <li>• “She is looking for death.”</li> </ul>
	22	Lack of interpersonal communication skills, no education or inabilities	<ul style="list-style-type: none"> <li>• “She does this to herself.”</li> <li>• “The reason is she spoils her husband.”</li> <li>• “She definitely has a bad attitude when she talks to her husband.”</li> <li>• “She doesn’t do housework at all, that’s how she pisses her husband off.”</li> <li>• “She is not independent and lazy.”</li> <li>• “She has no education, if not, her husband won’t act like this.”</li> <li>• “Her husband works hard for the family, she doesn’t care about him, of course he is angry.”</li> <li>• “She has never been in school, she can’t do things other educated people can, no wonder her husband is mad about her.”</li> </ul>
	19	Bad characters	<ul style="list-style-type: none"> <li>• “The reason is she is not confident.”</li> <li>• “Her weakness results in this.”</li> <li>• “She is introvert.”</li> <li>• “She grows a habit as being in bed.”</li> </ul>
Perpetrator blaming	29	Torturing	<ul style="list-style-type: none"> <li>• “He tortures her.”</li> <li>• “It is domestic violence.”</li> <li>• “He drinks, gambles and beats her.”</li> </ul>
	77	Being irresponsible	<ul style="list-style-type: none"> <li>• “If she has already taken care of him so much and he still acts like this, his problem, he shouldn’t (do this to her).”</li> <li>• “...he doesn’t care about her at all.”</li> </ul>
	8	Verbal abuse	<ul style="list-style-type: none"> <li>• “...he curses her on purpose.”</li> <li>• “He talks about her shortcomings and irritates her.”</li> <li>• “He gets drunk and loses in gambling, so he takes it all on her.”</li> </ul>
	12	Lack of understanding	<ul style="list-style-type: none"> <li>• “I blame her husband for not understanding her.”</li> <li>• “Her husband works away from home, she does everything at home, but when he comes back, he still doesn’t understand her contribution to the family.”</li> <li>• “He suspects she cheats.”</li> </ul>
	18	Despise	<ul style="list-style-type: none"> <li>• “...he is ashamed of her no education experience.”</li> <li>• “I blame him. He knows she is not well educated when he met her, but he still married her. Now he blames her for being not educated and he is afraid of losing his face.”</li> <li>• “He has saved some money when he works in the city, and she doesn’t make any money, so that he despises her.”</li> <li>• “The cause is he has money, men always turn bad once they have money, he begins to look down upon her.”</li> </ul>
	16	Cheating	<ul style="list-style-type: none"> <li>• “He has affairs, so he treats her bad.”</li> <li>• “She is too naïve, her husband cheats on her and bullies her.”</li> <li>• “He has changed when he works outside.”</li> <li>• “Her husband fools around with women outside.”</li> </ul>
	6	Disappointment	<ul style="list-style-type: none"> <li>• “He is gambling all the time and doesn’t listen to his wife nor any goals in life.”</li> <li>• “This husband is not a useful man, and he doesn’t care the family.”</li> <li>• “He hangs around and does nothing and fails his responsibility.”</li> </ul>

how the man defended his face (“face” referred to the dignity or prestige an individual processes in Chinese culture). One participant stated, “I blame him. He knows she is not well-educated when he met her, but he still married her. Now he blames her for being not educated and he is afraid of losing his face.”

## RELATIONAL FACTORS

There were 44 participants who believed that the cause was relational. Forty-one women attributed the problem to the

broken relationship between the couple, and examples were “They have been separated too long, and the relationship goes down,” “He works far away, now they don’t fit each other,” “They have problems in communicating with each other,” “It’s mutual, they don’t listen to or understand each other,” “... either one of them cheated the other,” and “...they have too many conflicts.” Three women attributed the problem to her lack of support, and their responses were “She can only get comfort when she moves back to her parents,” “She is alone at home, no one looks after her and no one understands her,” and “She needs support.”



## COMMUNAL AND SOCIETAL FACTORS

There were seven women who believed that the cause was community factors, and their responses were “Her family doesn’t have much money, they are poor,” “I think it’s her living environment,” “It’s her family,” “She is upset about family problems,” “Financial issues I guess, her family doesn’t have much money to live well, nor does her,” “They both work too hard and feel very tired, he drinks, gambles and she wants to stay in bed,” and “The family financial problem makes them suspicious to each other.”

There were 21 women who believed the cause was societal factors. Two women believed the cause was her fate, and their responses were “It’s her fate, she doesn’t have a good husband, and she can’t have a good life in the future,” and “It’s fate that made her born in the rural areas, so that she didn’t have a chance to go to school.” Nineteen women believed it was a common/normal scene in life and that there was no cause for anything, and examples were “...the couple quarrels, how common it is,” “No reason, no cause, there is nothing behind it,” and “I don’t think there is any problem or cause.”

## UNIDENTIFIED

Few participants had responses ( $n = 15$ ) that fell into the theme that we termed “unidentified.” These participants usually provided very brief responses and appeared to barely have insight on violent behaviors or confidence in discussing the cause. Common responses were “I don’t know” or “I can’t think about it.” Despite careful probing by interviewers, these participants had little to say; they may have lacked the language to discuss the story. For example, one woman stated, “It’s all about the young generation. I’m old and don’t know about these things for a whole life.”

## DISCUSSION

To our knowledge, this is the first qualitative study in China to elicit the perspectives—to hear the voice—of rural Chinese women and to explore how they understand the cause of IPV. This study fills a gap in the literature and provides findings to develop IPV interventions in rural China. We reported 15 participants who provided very brief responses and appeared to barely have insight on violent behaviors or confidence in discussing the cause; 252 participants attributed the conflicts to individual problems; 44 women believed the cause was relational; and 28 participants attributed the cause of IPV to communal and societal factors.

The WHO suggests the SEM when considering global violence as well. IPV studies have documented individual level risk factors to include younger age (37), lower level of education (38), financial dependence (39), previous violence experience (40), lower level of empowerment and lower social support (41), and childhood maltreatment experience (42). At the relational level, risk factors include multiple partners (43), male dominance in the family (44, 45), economic stress (34), poor family functioning and low social capital (46), and in-law conflicts (47). At the

communal level, risk factors include poverty (48) and weak community sanctions (46). At the societal level, risk factors include traditional gender and social norms, which support violence (33, 49, 50), ideologies of male entitlement (51), and weak legal sanctions (34).

We sought to understand rural women’s explanations to IPV based on the SEM as a framework, and we learned that the gender inequality in the traditional Chinese culture may have sculpted participants’ perspectives. IPV reflects the relationship power, and the more dominant males are, the more females will experience violence, regardless of countries/regions (52, 53). Confucianism deeply influences the Chinese traditional culture, which has been criticized for gender norms that belittle females, e.g., the lifetime doctrine, “*san cong si de*” (the three obediences that women should obey their fathers, serve their husbands’ need, and follow their sons; and the four virtues that include fidelity, tidiness, propriety in speech, and commitment to needlework) (50). The traditional Chinese gender concepts advocate a husband should be dominant, strong, and arbitrary in the family and within his relationship. On the other hand, a woman should be submissive to her husband and other male family members and obedient in her relationship (54). Traditional virtues such as “*san cong si de*” and “*san gang wu chang*” (the three rules and five constant virtues of Confucianism; those are ruler guides subject, father guides son and husband guides wife, benevolence, righteousness, propriety, wisdom, and fidelity) and “*nan zhu wai, nv zhu nei*” (men are responsible for outdoor affairs; women are responsible for indoor affairs) exactly reflect this inequality. Meanwhile, men who have attitudes that beating wives is acceptable are two times more likely to commit IPV than those who do not (42). Given this cultural background, rural women are very dependent on men. When conflicts arise, women often feel guilty and will not adopt appropriate coping strategies to reduce violence and protect their safety (55, 56). Hence, mitigating the patriarchal influences of traditional rural Chinese concepts may be an important first step for interventions to encourage help-seeking behaviors to reduce IPV.

When participants attributed IPV to relational problems, we believed it was related to the internal migration in China. Along with China’s economic development, the population of internal migrant workers, who were mainly males, increased. Consequently, the population of those left behind, mainly women (predominantly married), children, and elders in rural areas, increased (57–61). The separation of couples may reduce communication and mutual understanding due to the differences in urban and rural living experiences that would gradually increase the gap in how to cope with daily stress and solve relationship conflicts. Participants relayed that this may increase the risk of IPV in return. Chen’s study with a rural Chinese sample reported that the main causes for IPV were financial conflicts, gambling, substances abuse (smoking, drinking and drug abuse), personality conflicts, affairs, sex experience, and reproductive problems (62); further, the study reported women listed financial conflicts and men listed cheating as the primary cause of IPV, which raised a question worthy of further discussion and exploration. Why did women focus on financial conflicts and men focus on affairs? Chen’s study indicated the rural-to-urban

internal migration was at the societal level, and interventions should address its influence on IPV.

We need to consider the limitations of this study. First, we only implemented home interviews during daytime hours, thus missing women who had outside work, and we did not recruit female migrant workers living in distant cities. Consequently, we did not obtain the perspectives of women who may have been more independent. Second, though the vignette component of the SEMI has been shown to be useful in understanding participants' beliefs about diseases states and EMs of illnesses, it is possible that we would have elicited different responses had we asked the participants to describe their own experiences with IPV or to imagine themselves in the scenario described (63). Third, we coded participants' main responses in the analysis. While we did not record data to explore the inter-rater reliability of coding, we did use consensus. Nevertheless, this study's findings are an important first step, despite its limitations, in beginning to craft culturally appropriate IPV interventions in rural China.

## CONCLUSION

Despite the limitations, this is the first study that we are aware of that sought to hear rural women's voices about the causes of IPV. It is imperative to assess community members' perceptions of what causes IPV to create interventions to prevent and address this public health issues. We report that a majority of rural women attribute IPV to the victim's or perpetrator's personal problems, indicating that IPV interventions must consider raising a public awareness campaign about the risk factors of IPV and focus on reducing self-blame among victims. Liang's theory of help-seeking suggests that victims' decisions on whether and where to seek help are influenced by their living experiences, interpersonal social support system, and sociocultural norms; and these factors will also impact how victims identify IPV. China is rooted in traditional heteronormative cultural beliefs that women are subordinate to men. Our findings help in understanding the rural Chinese women's beliefs about the etiology of IPV, and we believe that to overcome cultural barriers and promote help-seeking behaviors, interventions should target cultural factors from each level of the SEM.

Fundamentally, we are concerned that many rural victims' experiences remain hidden due to barriers at multiple levels—cultural as well as lack of infrastructure (e.g., IPV shelters), lack of information about crisis call lines, lack of transportation to

seek help, and limited access to the legal and justice system. In this context, strategies to reduce the prevalence and impact of IPV in rural China should focus both on improving communities' capacities to prevent and respond to IPV and on disseminating processes that encourage help-seeking behaviors and fostering a new generation of social norms (64). These must be culturally attuned and adapted to the needs of China and implemented locally to have sustained impact.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the Ethics Committee of Sichuan University and the University of Rochester Research Subjects Review Board. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

## AUTHOR CONTRIBUTIONS

FH designed the study instruments, implemented the field study, monitored data collection, cleaned the data, developed the plan for analysis, analyzed the data, and drafted and revised the paper. CC designed the study instruments, trained interviewers, assisted with the analysis plan, revised the paper, and supervised FH. MW designed the study instruments, trained interviews, and revised the paper. EC initiated the project, revised the paper, and supervised FH. PQ initiated the project, designed the study instruments, monitored data collection, cleaned the data, and revised the paper. All authors had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All authors read and approved the final manuscript.

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# The Biopsychosocial Model and Perinatal Health Care: Determinants of Perinatal Care in a Community Sample

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Insufficient care in the perinatal period is associated with poorer maternal health, poorer perinatal outcomes, infant mortality, and health inequalities. Identifying the sources of and reducing the rates of insufficient care is therefore a major clinical and public health objective. We propose a specific application of the biopsychosocial model that conceptualizes prenatal and postpartum care quality as health markers that are influenced by psychological factors and family and social context. Clinic attendance data were abstracted from the electronic medical records of  $N = 291$  participants enrolled in a longitudinal pregnancy cohort study of healthy women who have been followed since the first trimester; the Kotelchuck Index (KI) was calculated as an index of perinatal care utilization. Detailed prenatal psychological, social, and sociodemographic data were collected from self-report questionnaire and interview. Bivariate analyses indicated socio-demographic (e.g., race), psychological (e.g., response to perceived racism, affective symptoms, trauma experience), and social and family context (e.g., social support, family size) significantly influenced pre- and post-natal care utilization. Multivariate logistic regression analyses, adjusting for medical complications, identified social and family context as robust predictors of perinatal care utilization. The findings underscore the need for biopsychosocial models of health care and highlight several potential strategies for improving health care utilization.

**Keywords:** prenatal care utilization, postpartum, attendance, biopsychosocial, maternal-fetal health

## INTRODUCTION

The biopsychosocial model, most closely associated with George Engel (1), was proposed as an alternative to the then-dominant biomedical model for understanding health and delivering healthcare. What distinguished the biopsychosocial model was an emphasis on individual needs, the social context of health and health care, and most especially the dependencies between an individual's biological processes underlying health and the social and cultural systems in which she/he is embedded. This model spurred a major conceptual shift: its foundation underlies current research paradigms (e.g., “social determinants of health”) and values for health care delivery (e.g., “patient-centered” care). Nonetheless, the model has been criticized for being difficult to operationalize (2).

Opportunities provided by a biopsychosocial model to improve health and health care delivery may be especially important in the perinatal period. That is because of the high prevalence and burden of pregnancy-related health conditions such as preeclampsia and gestational diabetes. More broadly, the rates of pregnancy-related morbidity and mortality are increasing in the United States (3) and the World Health Organization has stated that “ending preventable maternal mortality remains an unfinished agenda and one of the world's most critical challenges” (4). Applications of the biopsychosocial model's focus on psychosocial and cultural contexts may provide clues to improving perinatal health care and particularly health inequalities, which are pronounced and persisting for maternal morbidity and mortality. The application of a biopsychosocial model to perinatal health may also benefit both maternal and child health given two decades of reliable evidence from large-scale studies linking prenatal maternal psychological well-being with child's behavioral and physical health (5). We propose an application of the biopsychosocial model to perinatal health care that conceptualizes prenatal clinic attendance and utilization as a health marker that is influenced by psychological, psychosocial, and sociodemographic factors.

The Kotelchuck Index (KI) or the Adequacy of Prenatal Care Utilization (APNCU) is a validated and widely used measure of adequacy of prenatal care; it is identified as the recommended measure in the PhenX Toolkit. The KI classifies prenatal care utilization into inadequate (<50%), intermediate (50–79%), adequate (80–109%), and “adequate plus” (also referred to as intensive or excessive care, at 110% or greater), based on the percent of American College of Obstetricians and Gynecologists (ACOG) recommended visits received. Inadequate (usually combined with intermediate) care during pregnancy is associated with poorer maternal health (e.g., hospitalizations after delivery), lower birth weight, higher rates of prematurity, and infant mortality (6, 7). There remains some controversy about any causal connection between prenatal care utilization and maternal and child health outcomes. Nonetheless, improving quality and access to prenatal care remains a high clinical and public health priority and a widely suggested means for reducing disparities in maternal and child health outcomes. It is therefore an important target for clinical research.

Several risk factors of inadequate prenatal care utilization have been identified; much of the focus and most of the consistent findings concern socio-demographic characteristics. Women with low socioeconomic status, defined according to Medicaid eligibility, education, and neighborhood deprivation are more likely to receive inadequate prenatal care (8). Care utilization is also frequently associated with race and ethnicity. Black and Latinx women are at a greater risk for late initiation of care, not obtaining any care, and receiving inadequate prenatal care (8–10). In fact, maternal morbidity and mortality is one of the most acute examples of health disparities in the US. The reasons for associations between perinatal care utilization and socio-demographic or socio-economic factors are not well-understood and are likely to be complex and confounded. More fundamentally, sociodemographic factors are not proximal causes of variation in perinatal care utilization but may point to underlying causes, such as systemic racism. For example, Black and Latinx women experience several types of economic and social barriers that may explain lower rates of adequate prenatal care (11). There is also evidence that racism and perceived discrimination may predict lower rates of adequate prenatal care in Black and Latinx women (8, 12).

Socio-demographic and socio-economic factors are confounded by psychological and social context, e.g., insofar as stress associated with economic deprivation and discrimination can contribute to and be exacerbated by adverse mental health conditions (13, 14). Accordingly, by focusing on the inter-related connections between social, demographic, and psychological factors, a biopsychosocial model may provide a plausible, more complete, and more practical explanation for variation in perinatal care utilization. Moreover, a biopsychosocial model may provide plausible intervention targets to improve perinatal care utilization, i.e., to the extent that identified psychological or social factors are more modifiable than sociodemographic characteristics. Our development of a testable biopsychosocial model focused on identifying hypothesized sources of risk for poor prenatal care utilization from the extant literature—which typically examines single or limited factors in isolation—and considering possible confounding among these sources of risk.

There is a limited but growing evidence base linking KI with social and cultural context and psychological processes hypothesized by a biopsychosocial model (15, 16). Psychological symptoms, including impairments significant enough to warrant diagnosis, may directly or indirectly alter prenatal care utilization. For example, women with a psychiatric diagnosis, including substance use disorders, may enter prenatal care late and/or receive inadequate care (15, 16). The nature of the effect is not consistent across all studies, however, with some (17) finding that affective symptoms are associated with less than adequate care, but others (18) reporting affective symptoms increase care; other reports are inconclusive (19, 20). Variation in effects reported may be explained by the severity of and type of symptoms and confounding health risk and social and cultural context.

Interpersonal and relationship context are significant components of a biopsychosocial model that may also shape perinatal care utilization. One of the most active areas of research

concerns interpersonal violence (IPV). Wolf et al. (21) and Cha and Masho (22) reported that preconception and/or prenatal IPV was associated with inadequate prenatal care. One meta-analysis (23) found that women who experienced IPV had a decreased likelihood of attending at least four prenatal care visits during pregnancy; a separate meta-analysis (24) indicated that women with past-year experiences of IPV had a high likelihood of delaying or never seeking prenatal care. However, meta-analyses expose the variation in effects across study, perhaps related to the nature of how violence and abuse is assessed; several studies did not find reliable associations between IPV and prenatal care utilization (25).

Although most of the concern in the scientific and clinical literature is on inadequate care, there is a small but growing literature on the demographic, social, and psychological factors associated with intensive or excessive prenatal care. Whether or not intensive prenatal care may reflect the same kinds of social and psychological processes associated with excessive care utilization outside of pregnancy is unclear. What is emerging is that excessive or intensive care is not super-adequate, but may instead signal different kinds of risk, and may also be non-optimal in terms of maternal and child health outcomes. For example, intensive or excessive care is associated with higher risk of preterm birth and low birth weight (10) as well as low readiness for parenting and high psychosocial risk (19, 26). It is possible these associations exist primarily because high medical risk pregnancies require more frequent visits and therefore fall into the intensive category of the KI. At a minimum, these findings suggest that research on prenatal care utilization needs to consider both inadequate and intensive care patterns, and that the associations between psychosocial and interpersonal factors and care utilization may not be monotonic.

A further feature of the study is consideration of both prenatal and postnatal care utilization. ACOG recommends a postnatal appointment by 12 weeks postpartum because it has obvious benefits for tracking early infant and maternal health, including postpartum depression (27). Few studies have examined the predictors of postpartum visit completion, and only one to our knowledge has factored in prenatal attendance data. That study (28) found that low income, enrollment in Medicaid, unemployment, multiple children, and missed prenatal visits were significantly associated with an incomplete postpartum visit. We aim to replicate and extend these findings.

In the current study we consider how a biopsychosocial model may be applied to perinatal care and consider how variation in care is affected by an individual's psychological, interpersonal, and social context. We capitalized on an ongoing, prospective longitudinal pregnancy cohort that has several design features for advancing research on perinatal care utilization. First, we sampled women from community and university prenatal clinics and enrolled participants at the first trimester; that meant that we are examining variation in prenatal care unconfounded with delayed prenatal care, a limitation in prior studies [but see (29)]. Second, the sample was medically healthy (i.e., not greater than normal risk at enrollment), which provides leverage for assessing psychosocial factors unconfounded with medical risk status. Third, the diverse sample has been assessed at each trimester

with an extensive battery of psychological, health behavior, socio-demographic, and psychosocial measures. For example, in addition to assessing depressive and anxiety symptoms, we also measure pregnancy-related anxiety, which has been suggested to have distinct features and correlates with perinatal and child outcomes (30). We are therefore able to provide a detailed portrayal of the social and psychological contexts for prenatal care utilization, and analysis of competing explanations for variation in prenatal care utilization.

## MATERIALS AND METHODS

### Sample

The study sample (Understanding Pregnancy Signals and Infant Development, "UPSIDE") is a prospective longitudinal pregnancy cohort conducted at the University of Rochester Medical Center (URMC); it is part of the NIH Environmental influences on Child Health Outcomes (ECHO) program. Between December 2015 and April 2019, women were recruited in their first trimester of pregnancy from outpatient obstetric clinics affiliated with the University of Rochester. Eligibility criteria were: <14 weeks gestation; age 18 or older; singleton pregnancy; no known substance abuse or a history of psychotic illness; ability to communicate in English; not greater than normal medical risk and without major endocrine, metabolic or immune disorders. Women received prenatal care through URMC or a URMC affiliated clinic, making their clinic attendance records accessible to research staff. Participants were compensated for each research visit and provided transportation or compensated for parking if needed. The study is approved by the URMC Institutional Review Board; written consent was obtained from all participants. For the current study, we excluded women with incomplete clinic attendance data from the medical record and those who discontinued care within a URMC clinic during pregnancy; we also excluded women who developed major endocrine, metabolic or immune disorders after enrollment and women who did not have a live birth.

### Measures

Clinic attendance data were abstracted from the electronic medical record; demographic, psychological, social, and health data were collected from in-person interview or questionnaire at prenatal visits scheduled to coincide with a routine prenatal visit in Trimester 1, 2, and 3; data on child birth weight and gestational age were abstracted from the medical record.

### Clinic Attendance

The number of visits scheduled and the outcome of each of these visits (completed, canceled/rescheduled, no-show) was recorded from the medical record. The Kotelchuck Index (KI) or the Adequacy of Prenatal Care Utilization Index (6) was calculated in the standard manner as the ratio of the observed number of completed routine prenatal visits to the expected number of visits. The expected number of prenatal visits is based on the guidelines published by the American College of Obstetrics and Gynecology (ACOG) and is adjusted based on total gestational weeks and timing of initiation of care. The ratio of observed to

expected visits is categorized into one of five groups: no prenatal care, inadequate (<50%), intermediate (50–79%), adequate (80–109%), or intensive (110% or greater) care. For example, a woman who enters prenatal care in her first trimester and has a 40-week pregnancy is expected to receive 14 visits. None of the study participants received no prenatal care.

Postpartum visit attendance was analyzed as a binary variable, according to whether or not a postpartum visit was completed by 12 weeks postpartum, as recommended by ACOG. Women were considered to have not had a postpartum visit only if it was confirmed in the EMR.

Data was also collected on prenatal no-show visits. A visit was considered a no-show when a participant failed to attend her scheduled prenatal visit and did not call to cancel her appointment. More information on the methods and results for no-show data can be found in **Supplementary Table 1**.

## Birth Outcomes

Birth weight (g) and gestational age (weeks) based on ultrasound or last menstrual period were abstracted from the medical record.

## Health Predictors

Participant age, parity, pre-pregnancy body mass index (BMI), and smoking status (including vaping) was collected from questionnaire and interview at enrollment. A variable for pregnancy complications was created to encompass women who were diagnosed with pre-eclampsia, gestational diabetes, or gestational hypertension in the EMR.

## Social Predictors

### Demographics

Employment status (employed vs. unemployed; number of hours worked per week), education level (highest level attained), marital status (single vs. married/cohabiting), and number of household members (not including the participant) was collected from questionnaire and interview at enrollment. Self-reported race and ethnicity was recorded; we identified three groups sufficiently large enough for comparison: non-Hispanic White, non-Hispanic Black, Hispanic/Latinx; the small number of other groups and mixed race/ethnic groups were included in an “other” category for analysis purposes. The income to needs variable was calculated by taking a ratio of poverty level as determined by the US Department of Health and Human services (31) by annual income. Participants also indicated whether they utilized services from Women, Infants and Children (WIC), Medicaid, or other public assistance. Women were recruited from one of three types of obstetric clinics: clinics serving a high psychosocial need population (hereafter “Community Clinic”), general university obstetrics clinic, and a Midwifery Practice.

## Psychological Predictors

### Social Support

The Interpersonal Support Evaluation List (ISEL) (32) is a widely-used index of social support in the perinatal period that assesses perceived availability of instrumental and expressive support. Thirty out of the original set of 40 items were answered on a scale of 1 (definitely true) to 4 (definitely false), with higher scores

indicating higher perceived availability of support. The ISEL was administered at the second trimester study visit.

### Anxiety

The Penn State Worry Questionnaire (PSWQ) (33) is a widely-used 16-item instrument used to assess symptoms of anxiety and worry. Items range from 1 (not at all typical of me) to 5 (very typical of me); higher scores indicate more anxiety and worry.

### Pregnancy-Related Anxiety

Pregnancy-related anxiety was measured using a modified version of the Pregnancy Related Anxieties Questionnaire-Revised (PRAQ) (30) Three items assess anxiety and worry about the pain of delivery; four items assess anxiety and worry about the baby’s health.

### Depression

The Edinburgh Postnatal Depression Scale (EPDS) (34) is a widely-used 10-item scale to assess depression in the perinatal period independent of physical symptoms that could be confounded by pregnancy. Items are scored 0–3; higher scores indicate more depression.

### Interpersonal Violence

Interpersonal abuse and violence were assessed using a screener based on previously used tools (35, 36). The questions assess for current and past physical, sexual, and emotional abuse. The composite score (“interpersonal violence general”) was calculated by summing the three screening items. The IPV screening items were administered at the third trimester study visit.

### Stressful Life Events

The Stressful Life Events scale (SLE) (37) is a 26-item scale that asks about stressful events that may have happened to the participant during the last year and was developed specifically for pregnant samples. We assessed the total number of events as the measure of stress. The SLE was administered at the third trimester study visit.

### Discrimination

Three sections of the Experiences of Discrimination scales (EOD) (38) were adapted to measure discrimination based on race and ethnicity only. Response to Unfair Treatment is a 2-item measure assessing level of passivity in response to being treated unfairly based on race or ethnicity; higher score indicates greater passivity of response. The Discrimination scale asks participants to answer “yes” or “no” to whether they have experienced discrimination in 9 separate contexts; higher score indicates higher self-reported discrimination. The Everyday Discrimination scale contains 9 items to assess the frequency with which participants experience discrimination; higher score indicates less frequent discrimination.

## Statistical Analyses

The PSWQ, EPDS, and PRAQ were administered at each trimester; the final composites were averages of each of the three summed scores. After reporting descriptive statistics, we present bivariate analyses between the KI and obstetrics outcome and



**TABLE 1** | Sample descriptive data ( $n = 291^{a,b}$ ).

Maternal characteristics <sup>c</sup>	Mean (SD)	Mix-Max	N (%)
Age (years)	28.7 (4.7)	18–41	
Pre-pregnancy BMI (kg/m <sup>2</sup> )	28.3 (7.1)	15.3–49.1	
Household size (persons)	3.3 (1.4)	1–11	
Ethnicity/race			
Non-Hispanic White			159 (54.6)
Non-Hispanic Black			75 (25.8)
Hispanic			33 (11.3)
Asian			10 (3.4)
Other <sup>d</sup>			14 (4.8)
Education			
<High school			9 (3.4)
High school			88 (32.8)
Some college			41 (15.3)
College degree			65 (24.3)
Post-college degree			65 (24.3)
Employment status			
Employed			208 (73.5)
Unemployed			75 (26.5)
Marital status			
Married/living as married			163 (57.6)
Single			120 (42.4)
Medicaid enrollment			
Yes			111 (43.5)
No			144 (56.5)
Nulliparous			
Yes			96 (33.0)
No			195 (67.0)
Smoking during pregnancy (any)			
Yes			89 (31.4)
No			194 (68.6)
Pregnancy complications			
Yes			31 (10.7)
No			260 (89.3)
Enrollment clinic			
General OB			60 (20.6)
Midwifery			87 (29.9)
Community clinic			144 (49.5)
Infant characteristics <sup>e</sup>	Mean (SD)	Min-Max	
Gestational age (weeks)	39.4 (1.5)	32.1.1–42.7	
Birth weight (g)	3,362.6 (534.8)	1,280–4,730	

<sup>a</sup> $N = 326$  Upside participants considered for inclusion. Participants were excluded if: they transferred prenatal care out of UPMC during pregnancy, they did not have a live birth, they did not receive prenatal care within UPMC affiliated system, they became screen failures after enrollment.

<sup>b</sup> $N$ 's for individual variables may differ slightly due to missing data.

<sup>c</sup>At time of enrollment.

<sup>d</sup>"Other" including more than one race and American Indian/Alaska Native and individuals self-reporting as "other".

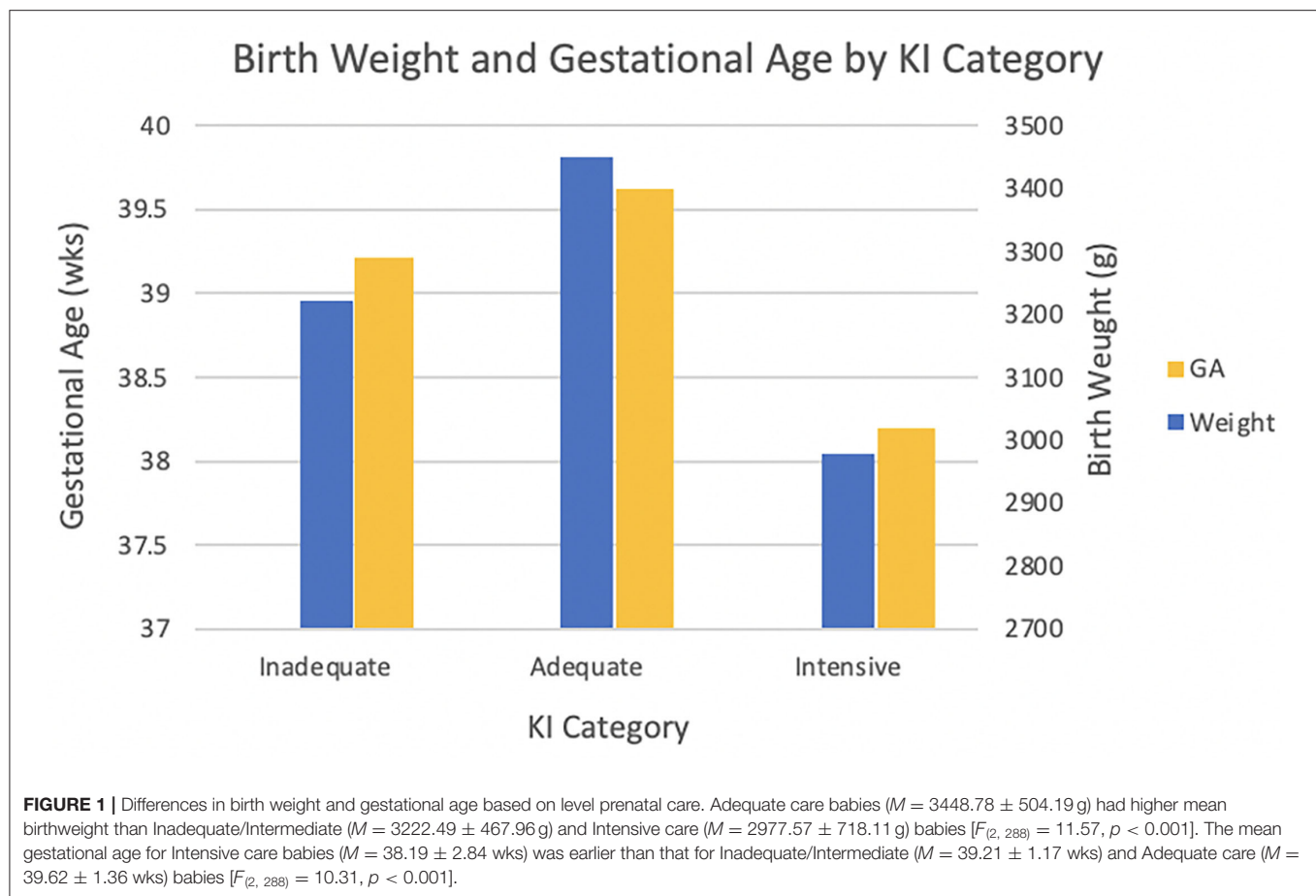
<sup>e</sup>See **Figure 1** for graph of infant characteristics by KI category.

predictor variables. Significant predictors of prenatal care ( $p < 0.05$ ) in bivariate analyses were included in a multivariate analysis to examine independent effects. We followed previous studies in categorizing prenatal care utilization as Inadequate/Intermediate, Adequate, and Intensive. For bivariate and multivariate results, Adequate care is the reference category. Two contrasts were examined: Adequate contrasted with Inadequate/Intermediate and Adequate contrasted with Intensive. For the multivariate analyses, data were analyzed using multinomial regression with Adequate as the reference category; odds ratio and significance is reported for each contrast. A similar strategy was employed for postpartum care utilization, with bivariate analyses preceding multivariate analyses. The dichotomized response for postpartum visits means that the sole contrast was between attendance at a postpartum visit (or not); For bivariate analyses using Analysis of Variance or chi-square analyses and multivariate analyses using logistic regression. All statistical analyses were performed in IBM SPSS Statistics (39). In addition to reporting analyses of the KI, we also report, for comparison purposes, parallel analyses for no-show visits (see **Supplementary Table 1**).

## RESULTS

Our analytic sample was composed of 291 (of the 326) participants in the cohort who met the inclusion and exclusion criteria. The majority, 70%, of the women received Adequate care compared with Inadequate ( $N = 6$ , 2%), Intermediate ( $N = 57$ , 20%), and Intensive ( $N = 23$ , 8%). Descriptive statistics (**Table 1**) indicate that 1/3 of the participants were first-time mothers, and just over half of the participants identified as non-Hispanic White (54.6%). The psychosocial risk-enriched nature of the sample is indicated by the percentage with high school education or less (36%), Medicaid recipient status (44%), and single-parent status (42%).

Prenatal care utilization was significantly associated with birth weight and gestational age (**Figure 1**) in this healthy, normal risk sample. Bivariate analyses indicated that prenatal care utilization was associated with multiple socio-demographic, psychological, and family and social context variables; differences were observed for both Inadequate/Intermediate and Intensive care compared with Adequate care (**Table 2**). Inadequate/Intermediate care was associated with race/ethnicity: compared to non-Hispanic whites, an increased likelihood of Inadequate/Intermediate care was observed for non-Hispanic Blacks ( $OR = 2.01$ , 95%  $CI$  [1.05, 3.87],  $p = 0.036$ ) (an increased likelihood of Inadequate/Intermediate care was observed for those in mixed or "other" group,  $OR = 3.10$ , 95%  $CI$  [1.20, 8.00],  $p = 0.019$ , but the interpretation is unclear because of the small size and heterogeneous composition). In addition, younger age was significantly associated with an increased likelihood of less than adequate care, as was larger household size (**Table 2**). Individuals who experienced Inadequate/Intermediate also differed from those who received Adequate care in reporting less social support ( $OR = 0.98$ , 95%  $CI$  [0.96, 1.00],  $p = 0.026$ ) and less pregnancy-related anxiety ( $OR = 0.96$ , 95%  $CI$  [0.93, 1.00],  $p = 0.014$ ).



A more novel finding concerned discrimination: those women who reported a more passive response to unfair treatment were more likely to experience less than adequate care ( $OR = 1.56$ , 95%  $CI$  [1.01, 2.42],  $p = 0.044$ ). However, discrimination based on the Everyday Discrimination scale was not associated with care utilization; in fact, only  $n = 4$  individuals reported experiencing discrimination on a health care setting. Rates of Inadequate/Intermediate care varied across clinic site: attending the midwifery clinic significantly predicted a lower likelihood of less than adequate care in comparison to the community clinic ( $OR = 0.46$ , 95%  $CI$  [0.23, 0.94],  $p = 0.033$ ).

Fewer factors differentiated women who received Adequate compared with Intensive care (Table 2). One notable finding was that an increased likelihood of Intensive care was associated with a history of sexual assault ( $OR = 3.50$ , 95%  $CI$  [1.12, 10.96],  $p = 0.031$ ).

The multivariate model predicting Inadequate/Intermediate or Intensive care relative to Adequate care is presented in Table 3. The overall model was significant [ $X^2_{(20)} = 36.32, p < 0.014$ ]. Despite the number of significant bivariate associations in Table 2, the multivariate model indicated that, adjusting for all other factors in the model, only larger household size predicted less than adequate care ( $OR = 1.26$ , 95%  $CI$  [1.00, 1.59],  $p = 0.048$ ). Table 2 also indicates that prenatal medical complications

were significantly associated with Intensive care ( $OR = 4.93$ , 95%  $CI$  [1.28, 18.96],  $p = 0.02$ ). The association between history of sexual assault and Intensive care was trivially changed from the bivariate to the adjusted multivariate model ( $OR$  of 3.5 and 3.38, with corresponding  $p$ -values of  $<0.05$ – $0.056$ , respectively).

### Postpartum Clinic Attendance

Of the 291 participants with prenatal attendance data, 277 also had postnatal attendance data, of whom 89.5% completed at least one postnatal visit within 12 weeks after childbirth. Table 4 identifies many factors associated with completion of a postpartum visit. Postpartum visit status was not significantly associated with either perinatal outcome that was associated with prenatal care utilization, that is, gestational age or birth weight ( $p$ 's  $> 0.1$ ).

Likelihood of completing a postnatal visit was significantly associated with smaller household membership, elevated pregnancy-related anxiety, elevated general anxiety/worry, increased social support, being employed, and Medicaid status. Postpartum visit completion was also significantly associated with prenatal care utilization: 73.3% of those with Inadequate prenatal care completed a postpartum visit compared with 93.4% of those in the Adequate and 100% of those in the Intensive KI group [ $X^2_{(2)} = 22.28, p < 0.001$ ].

**TABLE 2 |** Bivariate logistic regression analysis predicting inadequate and intensive prenatal care vs. adequate prenatal care.

Predictors	Less than adequate	Adequate	Intensive	N	Less than adequate vs. adequate care	Intensive vs. adequate care
	frequency (%)	frequency (%)	frequency (%)		OR (95% CI)	OR (95% CI)
Age (years)	27.5 (4.86)	29.2 (4.48)	28.4 (5.1)	291	<b>0.92** (0.87–0.98)</b>	0.96 (0.88–1.06)
Pre-pregnancy BMI (kg/m <sup>2</sup> )	28.6 (6.85)	27.9 (7.21)	30.26 (6.54)	291	1.01 (0.97–1.05)	1.04 (0.99–1.10)
Poverty income ratio	2.8 (2.13)	3.9 (4.40)	3.4 (2.85)	241	0.87 (0.75–1.00)	0.97 (0.84–1.11)
Household size (persons)	2.8 (2.05)	2.2 (1.21)	1.7 (0.86)	284	<b>1.29** (1.08–1.55)</b>	0.70 (0.45–1.11)
Employed hours/week	36.0 (16.14)	34.8 (11.21)	39.8 (11.68)	204	1.00 (0.98–1.04)	1.03 (0.99–1.07)
Depressive symptoms	6.1 (5.00)	5.7 (4.45)	7.3 (3.84)	287	1.02 (0.96–1.09)	1.07 (0.98–1.17)
Pregnancy anxiety (regarding baby)	17.6 (9.48)	21.5 (11.04)	22.5 (11.03)	290	<b>0.96* (0.93–0.99)</b>	1.01 (0.97–1.05)
Pregnancy anxiety (regarding labor)	17.6 (8.91)	19.6 (9.70)	21.3 (11.08)	290	0.98 (0.95–1.01)	1.02 (0.97–1.06)
Social support	95.0 (19.27)	100.9 (15.85)	103.1 (13.05)	263	<b>0.98* (0.96–1.0)</b>	1.01 (0.98–1.05)
Worry symptoms	42.9 (12.67)	44.4 (13.19)	47.4 (9.64)	287	0.99 (0.97–1.01)	1.02 (0.99–1.05)
Stressful life events	2.6 (3.54)	2.4 (2.65)	2.8 (2.81)	255	1.03 (0.03–1.14)	1.05 (0.90–1.23)
Response to unfair treatment	2.6 (0.76)	2.4 (0.63)	2.4 (0.49)	264	<b>1.56* (1.01–2.42)</b>	0.82 (0.35–1.92)
Experience discrimination	0.7 (1.27)	0.7 (1.46)	0.8 (1.68)	260	0.97 (0.78–1.21)	1.02 (0.73–1.42)
Everyday discrimination	48.5 (10.04)	50.04 (7.39)	50.4 (6.29)	263	0.98 (0.95–1.01)	1.01 (0.94–1.08)
Interpersonal violence general	0.4 (0.65)	0.5 (0.73)	0.8 (0.75)	260	0.80 (0.50–1.26)	1.60 (0.88–2.92)
Education	3.1 (1.28)	3.4 (1.24)	3.4 (1.27)	268	0.84 (0.66–1.07)	0.97 (0.69–1.37)
<b>Frequency (%)</b>						
Ethnicity/race				291		
Hispanic	15.2	69.7	15.2		0.97 (0.34–2.79)	2.39 (7.60–7.53)
Other	37.5	54.2	8.3		<b>3.10* (1.20–8.0)</b>	1.69 (0.34–8.48)
Non-Hispanic Black	29.3	64	6.7		<b>2.05* (1.07–3.95)</b>	1.15 (0.38–3.47)
White (Reference)	16	76.1	6.9			
Medicaid status				255		
Yes	21.6	71.2	7.2		1.18 (0.63–2.2)	0.89 (0.34–2.27)
No (Reference)	18.8	72.9	8.3			
Enrollment clinic				291		
Midwifery	14.9	79.3	5.7		<b>0.46* (0.23–0.94)</b>	0.71 (0.34–1.47)
General OB	26.1	62.3	11.6		0.41 (0.14–1.18)	0.25 (0.06–1.15)
Community clinic (Reference)	21.2	75.8	3.0			
Currently employed				283		
Yes (Reference)	21.2	70.2	8.7			
No	22.7	70.7	6.7		1.06 (0.56–2.02)	0.77 (0.27–2.16)
Marital status				283		
Married/cohabitating	21.5	72.4	6.1		0.92 (0.52–1.62)	0.53 (0.22–1.26)
Single (Reference)	21.7	67.5	10.8			
Nulliparous				291		
Yes	18.8	69.8	11.5		0.82 (0.44–1.53)	1.90 (0.79–4.5)
No (Reference)	23.1	70.8	6.2			
Smoking during pregnancy (any)				283		
Yes	23.6	71.9	4.5		1.11 (0.6–2.03)	0.44 (0.15–1.36)
No (Reference)	20.6	69.6	9.8			
Receive WIC services				256		
Yes	21.8	66.7	11.5		1.3 (0.68–2.48)	2.19 (0.86–5.55)
No (Reference)	18.9	75.1	5.9			
Receive public assistance				256		
Yes	19.0	73.0	7.9		0.93 (0.45–1.93)	1.01 (0.35–2.92)
No (Reference)	20.2	72.0	7.8			
History of sexual assault				259		
Yes	16.7	66.7	16.7		0.86 (0.30–2.40)	<b>3.5* (1.11–10.96)</b>

(Continued)

**TABLE 2 |** Continued

Predictors	Less than adequate	Adequate	Intensive	N	Less than adequate vs. adequate care	Intensive vs. adequate care
	frequency (%)				OR (95% CI)	OR (95% CI)
No (Reference)	21.4	73.4	5.2	258		
History of abuse						
Yes	15.0	76.3	8.8		0.59 (0.29–1.2)	1.45 (0.52–3.99)
No (Reference)	23.6	70.8	5.6	260		
Physical domestic violence						
Yes	23.1	69.2	7.7		1.18 (0.31–4.5)	1.25 (0.15–10.5)
No (Reference)	20.6	72.9	6.5	291		
Prenatal medical complications <sup>a</sup>						
Yes	17.6	67.6	14.7		0.56 (0.19–1.70)	2.31 (0.78–6.84)
No (Reference)	21.1	73.6	5.3			

<sup>a</sup>Diagnosed with gestational hypertension, gestational diabetes, or pre-eclampsia.

\*\* $p < 0.01$ , \* $p < 0.05$ .

The bold indicates that this value is statistically significant.

**TABLE 3 |** Multinomial logistic regression analysis predicting inadequate and intensive prenatal care vs. adequate prenatal care ( $n = 240$ ).

Predictors	Less than adequate vs. adequate care OR (95% CI)	Intensive vs. adequate care OR (95% CI)
Age (years)	0.95 (0.87–1.03)	0.97 (0.86–1.09)
Household size (persons)	<b>1.26 (1.00–1.59)*</b>	0.88 (0.55–1.40)
Pregnancy anxiety (regarding baby)	0.97 (0.93–1.00)	1.01 (0.96–1.06)
Social support	0.99 (0.97–1.01)	1.00 (0.97–1.05)
Response to unfair treatment	1.21 (0.72–2.04)	0.90 (0.34–2.37)
Ethnicity/race		
Hispanic	0.51 (0.13–2.06)	2.86 (0.62–13.08)
Other	<b>5.63 (1.64–19.37)**</b>	3.84 (0.56–26.25)
Non-Hispanic Black	0.72 (0.29–1.77)	0.85 (0.19–3.76)
White (Reference)		
History of sexual assault		
Yes	0.33 (0.08–1.39)	3.38 (0.97–11.75)
No (Reference)		
Prenatal medical complications		
Yes	1.06 (0.32–3.47)	<b>4.93 (1.28–18.96)*</b>
No (Reference)		

\*\* $p < 0.01$ , \* $p < 0.05$ .

The bold indicates that this value is statistically significant.

Results from the multivariate model (**Table 5**) indicated that prenatal care utilization independently predicted completion of a postpartum visit, as did elevated social support and employment status; none of the other variables significantly predicted postpartum visit independent of other variables in the model.

## DISCUSSION

The current study leveraged several design strengths of a large, prospective, longitudinal pregnancy cohort study to test core components of a biopsychosocial model of perinatal health care

utilization. Congruent with predictions from a biopsychosocial model, perinatal health care utilization was associated with a diversity of social context, psychological, and socio-demographic factors. Multivariate model results highlighted the overlapping nature of these predictors, and identified social support, family context (size), anxiety, and trauma as among the more robust predictors of perinatal care utilization. We consider how the findings advance research in the area, and then consider several possible clinical applications for increasing perinatal care utilization.

The portion of women who received adequate or intensive care in our study, 78%, is comparable to other studies, including



**TABLE 4 |** Bivariate logistic regression analysis predicting completion of postpartum visit.

Predictors	Completed visit	Did not complete visit	N	Did vs. did not complete visit
	frequency (%)	frequency (%)		(df) $\chi^2$
Age (years)	29.04 (4.57)	27.48 (4.84)	277	(1, 275) 2.98
Pre-pregnancy BMI (kg/m <sup>2</sup> )	28.20 (7.17)	28.73 (6.52)	277	(1, 275) 0.14
Poverty income ratio	3.88 (4.15)	2.30 (2.01)	231	(1, 229) 3.50
Household size (persons)	2.14 (1.33)	3.10 (2.18)	271	<b>(1, 269) 11.62**</b>
Employed hours/week	35.50 (12.03)	33.47 (17.09)	197	(1, 195) 0.41
Depressive symptoms	6.03 (4.54)	5.15 (4.46)	275	(1, 273) 0.93
Pregnancy anxiety (regarding baby)	21.70 (11.11)	15.66 (5.51)	277	<b>(1, 275) 8.32**</b>
Pregnancy anxiety (regarding labor)	19.98 (9.61)	17.79 (9.20)	277	(1, 275) 1.36
Social support	101.03 (15.74)	88.83 (19.53)	257	<b>(1, 255) 12.46**</b>
Worry symptoms	45.10 (12.70)	39.66 (11.80)	275	<b>(1, 253) 4.53*</b>
Stressful life events	2.52 (2.95)	2.04 (1.99)	250	(1, 248) 0.63
Response to unfair treatment	2.47 (0.65)	2.44 (0.71)	259	(1, 257) 0.05
Experience discrimination	0.75 (1.46)	0.48 (1.26)	255	(1, 253) 0.78
Everyday discrimination	49.52 (8.16)	50.92 (6.24)	258	(1, 256) 0.69
Interpersonal violence general	0.48 (0.73)	0.46 (0.59)	255	(1, 253) 0.02
Education	3.4 (1.22)	2.92 (1.41)	255	(1, 253) 3.30
	<b>Frequency (%)</b>			<b>(df) <math>\chi^2</math></b>
Ethnicity/race			277	(3) 6.53
Hispanic	93.3	6.7		
Other	83.3	16.7		
Non-Hispanic Black	82.9	17.1		
White	92.8	7.2		
Medicaid status			248	<b>(1) 4.73*</b>
No	93.6	6.4		
Yes	85.2	14.8		
Enrollment clinic			277	(2) 1.15
Midwifery	90.6	9.4		
Community clinic	87.5	12.5		
General OB	92.2	7.8		
Currently employed			270	<b>(1) 4.28*</b>
Yes	91.5	8.5		
No	82.6	17.4		
Marital status			270	(1) 2.51
Married/cohabiting	91.8	8.2		
Single	85.7	14.3		
Nulliparous			277	(1) 3.73
Yes	94.6	5.4		
No	87.0	13.0		
Smoking during pregnancy (any)			270	(1) 0.55
No	90.2	9.8		
Yes	87.2	12.8		
Receive WIC services			249	(1) 0.37
No	90.8	9.2		
Yes	88.4	11.6		
Receive public assistance			249	(1) 0.18
No	90.4	9.6		
Yes	88.5	11.5		
History of sexual assault			254	(1) 0.31
Yes	93.3	6.7		
No	90.2	9.8		

(Continued)

**TABLE 4 |** Continued

Predictors	Completed visit	Did not complete visit	N	Did vs. did not complete visit
	frequency (%)			(df)X <sup>2</sup>
History of abuse			253	(1) 0.49
No	91.4	8.6		
Yes	88.6	11.4		
Physical domestic violence			255	(1) 1.42
Yes	90.1	9.9		
No	100.0	0.0		
Childhood sexual abuse			256	(1) 0.26
No	91.0	9.0		
Yes	88.2	11.8		
Prenatal medical complications			277	(1) 3.93
No	88.3	11.7		
Yes	100.0	0.0		

\*\* $p < 0.01$ , \* $p < 0.05$ .

The bold indicates that this value is statistically significant.

**TABLE 5 |** Multivariate binary logistic regression analysis predicting completion of postpartum visit.

Predictors	Did vs. did not complete postpartum visit OR (95% CI)
Household size	0.90 (0.68–1.17)
Pregnancy anxiety (regarding baby)	1.05 (0.98–1.12)
Social support	<b>1.04** (1.01–1.07)</b>
Worry symptoms	1.04 (1–1.09)
KI category	
Inadequate	<b>0.21** (0.08–0.57)</b>
Adequate/intensive (Reference)	
Medicaid status	
Yes	0.90 (0.30–2.73)
No (Reference)	
Currently employed	
Yes	<b>2.86* (1.02–8.03)</b>
No (Reference)	

\*\* $p < 0.01$ , \* $p < 0.05$ .

The bold indicates that this value is statistically significant.

those with diverse samples (10). Our reported rate of inadequate care (as distinct from intermediate care) of 2% matches other studies that have been actively following women in pregnancy, such as the rate of 2.4% in one controlled trial in pregnancy (26). On the other hand, this rate is lower than other studies not requiring participant engagement in an intensive prenatal assessment, e.g., rates of 10% or higher have been reported (7, 19). As regards postnatal care utilization, comparatively few of our study participants, ~10%, did not complete at least one visit within the recommended timeframe. Rates twice as high have been reported (28). The explanation may also reflect a

possible bias of engagement in a research study. Participation in the research study did provide incentives (compensation was provided for prenatal research visits that occurred in the same clinic women received their prenatal care) and perhaps an implicit social support or other inducement to attend perinatal health care visits. Alternatively, study participation may not have had any causal role in increasing perinatal care utilization, e.g., to the extent that women who are already very engaged in their prenatal care may be more disposed to participate in a research study on pregnancy and child health. We were unable to test this hypothesis directly because we were not able to compare perinatal care utilization in those women who refused participation in the study.

A starting point for our analyses predicting prenatal care utilization is the observation that there were significant group differences in both gestational age and birth weight among the Adequate, Inadequate/Intermediate, and Intensive care utilization groups. Those who received adequate care according to ACOG guidelines had the most positive perinatal outcomes. The magnitude of effect was not large but nonetheless notable in this healthy sample of women, all of whom started prenatal care by the first trimester. The findings underscore the value in targeting prenatal care utilization for improving health outcomes even in normal to low-risk samples. Postnatal care visit utilization was not associated with these same perinatal outcomes but may be more relevant for maternal postnatal health and screening, which was not assessed in this study.

The biopsychosocial model proposes that health and health care is best seen as a system embedded in, and reflective of, the complex social context. We operationalized and tested this model by analyzing potential sources of variability in perinatal health care utilization. The findings provide broad-based support for the model: we identified a wide range of social and personal psychological factors that, at least in bivariate analyses, associated with pre- and post-natal care

utilization. These factors included affective symptoms of anxiety and worry, which generally increased care utilization; social support, which promoted adequate pre- and post-natal care; and family size, which decreased likelihood of adequate perinatal care and may index something of the practical difficulties of obtaining care or the increased organization and arrangements needed to access care. In fact, social and personal factors were more reliable predictors of pre- and post-natal health care than conventional health markers such as BMI or other health behaviors; the positive association between prenatal complications and intensive prenatal care was the exception to this general pattern. Social and psychological factors were also more reliably associated with perinatal care utilization than socio-economic factors, including education, income, and social services use. These findings emphasize that health care access or utilization is a product of social and behavioral forces. The predictability of postnatal care utilization from prenatal care utilization may reflect stable personal traits or social context.

Several additional findings deserve particular attention. As reported by many others, women who identify as non-Hispanic Black were more likely to experience less than adequate prenatal care in bivariate analyses; this did not extend to postpartum care, however. This association for prenatal care was not confirmed in multivariate analyses that considered multiple and confounding social and socio-demographic factors. This suggests that the other variables in the model accounted for, or were at least confounded with, race/ethnic differences in care utilization. The implication is that the widely-reported differential take-up of or access to health care in certain minority groups may be explicable in terms of confounding social and demographic factors that may be plausible targets for improving perinatal health care utilization. That, too, is consistent with the biopsychosocial model's emphasis on the embedded and confounded natures of risks.

A second findings concerns the role of trauma history. Individuals who reported sexual trauma in the course of the research study were more likely to experience intensive prenatal care. This was contrary to previous findings associating past and current IPV with late or inadequate prenatal care (24). The implication is that sexual trauma history is associated with increased care seeking rather than providers responding differentially to women with a trauma history (although we are unable to rule out the latter possibility). In this context, it is important to note that intensive care is not associated with better outcomes, at least as regards birth weight and gestational age.

The third finding demonstrated that, in the bivariate analysis, pregnancy-related anxiety specific to concerns about the baby were related to a *decreased* likelihood of less than adequate prenatal care, as well as a *higher* likelihood of completing a postpartum visit. Ours is the first study we are aware of that examined pregnancy-specific anxiety in relation to prenatal care utilization patterns across pregnancy and beyond. Pregnant women who have anxiety related to the well-being of their child may be more inclined to desire assistance and assurance from professional care providers, thereby making them less likely to deviate from their attendance from a recommended schedule of prenatal care visits. This pattern of anxiety and care utilization is well-established outside of the perinatal care context (40), and

may have implications for improving clinical outcomes while also reducing health care costs.

Several limitations of the study should be noted. The first is that the findings may not generalize to all samples of interest. We chose to study a generally health group of women who initiated prenatal care by the first trimester to examine biopsychosocial influences unconfounded with medical risk. Our focus on the current cohort also meant that the women were followed more closely (as a function of study participation, and they did receive compensation for prenatal research visits) than would be typical. In addition, although the study was comparatively large, it was not positioned to examine perinatal care utilization for all ethnic/minority groups; in particular, our finding of increased likelihood of less than adequate care among the small and diverse participants who did not identify as Hispanic, non-Hispanic Black or non-Hispanic white requires further investigation. Third, we did not have sufficient data to examine clinic characteristics that may explain variation in perinatal care utilization; our explanatory focus was limited to characteristics of the women in the study. Finally, the Kotelchuck Index, although well-validated and commonly used in research, is limited in its ability to measure care quality because it does not capture the actual visit content. Elements of the visit that are crucial for determining care quality—provider-patient communication, patient satisfaction, and health outcomes—are not considered in this index. It is also important to consider the possibility that patients who have experienced racial discrimination in maternal health care settings may have been reluctant to reveal their experiences in a survey administered in the context of such settings. Research incorporating mixed-methods approaches that include qualitative interviews may be valuable in providing additional insight into the nature of extent of care quality. Set against these limitations were several strengths of the study, including a detailed assessment of social context, psychological, and demographic factors; a multivariate approach that considered overlapping and competing predictors of less than adequate and intensive care; and a consideration of care utilization in pregnancy and the early postpartum period.

Several clinical applications are suggested by the findings. For example, the results concerning race and response to unfair treatment suggest that women who prefer to avoid confronting structural racism are more vulnerable to inadequate prenatal care, which may make the hospital environment uncomfortable. The implication may be that outreach and trust-building experiences may be needed to improve health care utilization. Additionally, increased psychosocial screening at prenatal appointments—particularly in the early stages of pregnancy—may identify patients at elevated risk for poor attendance or worse birth outcomes, and could be clinically and cost-effective. Targeting interpersonal violence, which is now routine in most settings, as well as affective symptoms and family setting may also identify those at greatest risk for inadequate care. Third, in contrast to socio-demographic or socio-economic indicators, many of the predictors of perinatal care utilization identified here, such as affective symptoms, are modifiable, and may be responsive to brief targeted interventions to complement routine obstetric care.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Rochester Medical Center Research Subjects Review Board. The patients/participants provided their written informed consent to participate in this study.

## AUTHOR CONTRIBUTIONS

ZD, TO'C, and LP were involved in the literature review and manuscript writing. JB, CI, and ZD did the medical record abstraction and data cleaning. SB, ZD, and TO'C conducted

data analyses. JB, JM, and MB formatted tables and figures. EPr, EPo, LT, KB, EB, and RM provided guidance from a clinical perspective and they also provided comments on multiple rounds of drafts. All authors contributed to the article and approved the submitted version.

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## SUPPLEMENTARY MATERIAL

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# URMC Universal Depression Screening Initiative: Patient Reported Outcome Assessments to Promote a Person-Centered Biopsychosocial Population Health Management Strategy

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**Background:** Patient-reported outcomes (PROs) can promote person-centered biopsychosocial health care by measuring outcomes that matter to patients, including functioning and well-being. Data support feasibility and acceptability of PRO administration as part of routine clinical care, but less is known about its effects on population health, including detection of unmet healthcare needs. Our objectives were to examine differences in rates of clinically significant depression across sociodemographic groups and clinical settings from universal depression screens in a large health system, estimate the number of patients with untreated depression detected by screenings, and examine associations between biopsychosocial PROs—physical, psychological, and social health.

**Methods:** We analyzed data from over 200,000 adult patients who completed depression screens—either PROMIS (Patient Reported Outcomes Measurement Information System) or PHQ-2/9—as part of routine outpatient care.

**Results:** Depression screens were positive in 14.2% of the sample, with more positive screens among younger vs. older adults, women vs. men, non-White vs. White, and Hispanics vs. non-Hispanics. These same sociodemographic indicators, as well as completing screening in primary care (vs. specialty care) were also associated with greater likelihood of detected depression in the medical record.

**Discussion:** Universal screening for depression symptoms throughout a large health system appears acceptable and has the potential to detect depression in diverse patient populations outside of behavioral health. Expanded delivery of PROs to include physical and social health as well as depression should be explored to develop a clinically-relevant model for addressing patients' biopsychosocial needs in an integrated fashion across the health system.

**Keywords:** depression, patient-reported outcomes measure (PRO), patient-centered care, biopsychosocial, health system, patient reported outcomes measurement information system (PROMIS), PHQ-9, depression screening

## INTRODUCTION

Patient-reported outcomes (PROs) can promote person-centered biopsychosocial health care by measuring outcomes that matter to patients, including functioning and well-being (1). UR Medicine implemented PRO screenings for physical, social and mental health in a range of settings with integration into the electronic medical record (EMR) for clinicians to use during patient visits (2). Data support feasibility and acceptability of PRO administration as part of routine clinical care, with positive effects on patient experience (2, 3). Less is known about its effects on population health, including detection of unmet healthcare needs, especially for psychosocial health indicators.

The current study presents data from over 200,000 patients who completed depression PRO screens—either PROMIS (Patient Reported Outcomes Measurement Information System) (4) or PHQ-2/9 (5, 6)—as part of routine outpatient care. We chose to focus on depression screening in adults because depressive symptoms impact numerous health outcomes, contribute to significant disability, and depression is a recommended screening domain in primary care. Well-validated systems for tracking depression as a PRO may improve identification of depressive disorders outside behavioral health settings and provide information that can improve outcomes for numerous health conditions in a biopsychosocial model of care.

Both the PROMIS depression screen (7–11) and the PHQ-9 (12) have been validated across diverse sociodemographic groups and have been shown to reliably detect clinically significant depressive symptoms across gender, race/ethnicity, and age. In addition, although these studies using these measures reliably demonstrate higher rates of clinically depressive symptoms among women, differences across race/ethnicity are inconsistent across studies. Major Depressive Disorder is often reported as less prevalent among racial/ethnic minorities compared to non-Hispanic Whites in community-based samples when controlling for socioeconomic status; (13–15) however, some studies examining the PHQ-9 have demonstrated higher rates of clinically significant depressive symptoms among Black and Hispanic adults (12, 16, 17). Research is needed to compare rates of clinically significant depressive symptoms in clinical (vs. community) samples for patients of diverse racial and ethnic backgrounds. Little is known about how effective universal screening for depression may be in detecting untreated depression across diverse sociodemographic groups and clinical settings, especially with PROs. In addition, the PROMIS measures of patient-reported outcomes, developed as part of the NIH Roadmap initiative, include not only psychological dimensions of health (e.g., depression) but also physical and social domains as well. There could be advantages to examining biopsychosocial dimensions of health and functioning during brief PROs screens, but little is known about such a strategy.

Data from this study were collected as part of universal screening for depression conducted outside of behavioral health clinics using a web-based platform called UR VOICE (University of Rochester Validated Outcomes In the Clinical Experience), which runs on tablets provided to patients at check-in for office visits (2, 18, 19). UR VOICE administers the

Patient Reported Outcomes Measurement Information System (PROMIS) measures as well as the PHQ-2/9. URM uses PROs to measure biopsychosocial conditions across the health system, including depression and anxiety, physical function, social roles and activities, and pain interference. PRO data is available immediately to clinical providers and viewed in the electronic medical record and can be discussed during clinic visits with patients to promote shared decision making. Given these data were collected as part of routine standard of care, clinical settings selected PROs most relevant to their patient population, with variability in measures across settings.

For this study, we focused on a cohort of patients who completed depression screens *via* universal screening in outpatient clinics, either PROMIS Depression or PHQ-2/9. We used a validated crosswalk of PROMIS depression and PHQ-2/9 scores (20, 21) to analyze depression screens with a standardized T-score metric and associated norms. We defined positive depression screens as T scores of 60 or greater, which corresponds to a symptom severity level of moderate (or severe). This was selected as the threshold for clinical significance given that this level of symptomatology is reliably associated with the presence of a Major Depressive Episode (6, 21). We examined the proportion of patients with positive screens who did not have documented mood disorder diagnoses in the year prior to or following the screen as an indicator of whether the diagnosis was identified (or missed) by providers (and thus whether treatment may have been provided). Our objectives were:

1. To examine the number of patients with clinically significant depressive symptoms detected by universal screening with PROs in a large health system (including variation across sociodemographic groups and clinical settings);
2. To estimate the number of patients with clinically-significant depressive symptoms detected by the screening who were likely not receiving treatment across sociodemographic groups and clinical settings; and,
3. To examine associations between biopsychosocial PROs—physical, psychological (depression), and social health.

## METHODS

### Participants

Data come from the EMRs of 206,468 adult patients (age 18 or older) in the UR Medicine system who completed depression screens (either PROMIS depression or PHQ-2/9) prior to healthcare visits from 2015 to 2018 as part of universal screening in several settings, including primary care, orthopedics, urology, and pain clinics. This study was approved by the University of Rochester IRB; specifically, IRB approval was granted for use of PRO data gathered as part of routine clinical care, with de-identified data provided to URM researchers.

### Procedures

Data used in these analyses, including PRO scores for depression, physical function, and social function, were extracted from the EMR. The index visit was the visit for which the patient completed the first documented depression screen using UR

VOICE at check-in. Some patients were established patients completing the tablet screening for the first time, while others were new patients who began care at the clinic when screening procedures were in place. Many patients completed follow-up depression screens, but those data are not used in the current study.

## Measures

Demographics were extracted for the index visit (age, sex, race, and ethnicity). Mood disorder diagnoses were extracted from the EMR with a positive diagnosis if any of the following ICD codes were present in the 12-months prior to and following the index visit date: any F30 codes (Manic episode); any F31 codes (Bipolar disorder); any F32 codes (Major depressive disorder, single episode); any F33 codes (Major depressive disorder, recurrent); any F34 codes [Persistent mood (affective) disorders]; and any F39 codes [Unspecified mood (affective) disorders].

## Depression PRO Screens

Scores for depression were extracted from the EMR. Patient responses generate a standardized psychometric T score comparing the patient's responses to the population mean, with a T score of 50 corresponding to the mean of the reference population and a standard deviation of 10. All patients completed depression screens at the index visit. Patients who completed the depression screen in primary care clinics completed the Patient Health Questionnaire-2/9 (the tablet stopped administration after PHQ-2 if patients did not screen positive on those items), while patients in all other clinical settings completed the PROMIS depression computerized adaptive test (CAT). PHQ-2/9 scores were converted to T scores using validated "cross-walk" tables (21). Depression T scores  $\geq 60$  (one standard deviation above average, considered "moderate" depression) were coded as positive screens. For patients who completed the PHQ-9, this corresponds to a score of at least 10.

## Physical and Social Function PRO Screens

Patients in some clinics also completed additional PROMIS measures. Patients who completed depression screens in orthopedic clinics also completed the PROMIS Physical Function CAT. Patients who completed depression screens in urology clinics also completed the PROMIS "Social Roles and Activities" CAT, which assesses social functioning (part of the PROMIS "Social Health" domain). As with depression PROs, patient responses generate T scores with a mean of 50 and standard deviation of 10, but for these domains, higher scores indicate greater (better) physical and social function.

## Data Analysis

For our first objective, to examine rates of clinically significant depression (using PROs) across sociodemographic groups and clinical settings, we used *t*-tests and analyses of variance (ANOVA) to compare Depression T scores across demographic groups and clinical settings; we also conducted comparable analyses using a binary variable representing the presence of absence of a positive depression screen and conducted chi-square tests to compare the proportion of positive screens

across sociodemographic groups and clinical settings where screens were conducted. For our second objective focused on the number of patients with positive screens, we examined the proportion who had documented mood disorder diagnoses in order to estimate the number of "missed" diagnoses (i.e., proportion of all patients who screened positive for depression who did not have documented mood disorder diagnoses) across demographic groups and clinical settings; to do so, we used chi-square tests. We also examined differences in demographic make-up of patients who were screened across different clinical settings using chi-square tests, and then used analyses of covariance (ANCOVA) and logistic regression to further examine differences in screens and diagnoses across clinical setting while adjusting for demographic variables given significant differences in demographics across clinical settings (e.g., older age in orthopedic clinics). This allowed us to test whether clinic differences were primarily due to variations in population demographics by clinical setting. For our third objective, we computed correlation coefficients between the biopsychosocial PROs scores and also compared depression T-score means on physical and social health for those with and without positive depression screens.

## RESULTS

**Table 1** presents sample characteristics, including sex (55.9% female), race (81.4% White), ethnicity (91.5% non-Hispanic), and age (mean 51.29 years,  $SD = 17.85$ ). UR Medicine is in the city of Rochester, NY, within Monroe County; the race and ethnicity distribution of our sample is less diverse than the city of Rochester, NY, which has a higher proportion of Black (39.8%) and Hispanic (19.2%) individuals, but comparable to that of Monroe County (16.2% Black, 9.2% Hispanic/Latino). Most screens were conducted in orthopedic clinics, as these clinics were the first to initiate standardized procedures for collecting PROs.

Results for our first objective indicated that depression screens were positive in 14.2% of the sample ( $n = 29,314$  out of 206,468 patients). Significant differences were found in the prevalence of positive screens as a function of demographics (**Table 2**, all statistically significant,  $p < 0.001$ ): more positive screens among younger vs. older adults (15.1 vs. 11.6%), and women vs. men (16.0 vs. 12.0%), consistent with prior research on sociodemographic differences in the prevalence of depression. Of note, there were significantly more positive screens among non-White vs. White (22.4 vs. 12.5%) and Hispanics vs. non-Hispanics (26.4 vs. 13.7%). Specifically, patients of "Other races" (25.9%) had significantly more positive screens than White, Black, or Asian patients; due to limitations with data on race in the EMR, it is not possible to characterize those listed as "Other," as this may refer to patients who select "Other" *via* the patient portal, as well as clinic staff or providers selecting "Other" for the patient. This category may include bi-racial individuals, those who identify most with a specific nationality, as well as those who identify (or are identified as) primarily as Hispanic/Latino rather than a specific race. Positive screens were also significantly more



**TABLE 1 |** Sample characteristics.

Variable	M (SD) or n (%)
<b>Sex</b>	
Female	115,332 (55.9%)
Male	91,129 (44.1%)
Missing/Other	7 (0.0%)
<b>Race</b>	
White	168,089 (81.4%)
Asian	2,871 (1.4%)
Black	25,314 (12.3%)
Other	7,333 (3.6%)
Missing/Unknown	2,861 (1.4%)
<b>Ethnicity</b>	
Not Hispanic	188,817 (91.5%)
Hispanic	8,813 (4.3%)
Missing/Unknown	8,838 (4.3%)
<b>Age in years</b>	51.29 (17.85)
<b>Age groups</b>	
Younger (<65 years)	154,730 (74.9%)
Older (≥65 years)	51,738 (25.1%)
<b>Clinics</b>	
Orthopedics	135,182 (65.5%)
Surgery	6,533 (3.2%)
Primary care	27,112 (13.1%)
Oncology	3,397 (1.6%)
Specialty clinics	26,390 (12.8%)
Missing/multiple/other	7,854 (3.8%)
<b>PROMIS depression T score</b>	48.87 (9.94)
<b>PROMIS depression screen</b>	
Positive (T ≥ 60)	29,314 (14.2%)
Negative (T < 60)	177,154 (85.8%)
<b>PROMIS physical function T score, n = 179,094</b>	43.53 (10.23)
<b>PROMIS social satisfaction T score, n = 1,425</b>	47.63 (10.55)
<b>Mood disorder diagnosis</b>	
Diagnosis	26,946 (13.1%)
No diagnosis	179,522 (86.9%)
<b>PROMIS depression/diagnosis match</b>	
Positive screen, diagnosed	9,335 (4.5%)
Positive screen, not diagnosed	19,979 (9.7%)
Negative screen, diagnosed	17,611 (8.5%)
Negative screen, not diagnosed	159,543 (77.3%)

Sample N = 206,468. If variable had missing data for some subjects, completed n is noted. The following clinic groups included: Orthopedics/Pain (Orthopedic Surgery, Pain Medicine, Physical/Occupational Therapy, Physical Medicine and Rehabilitation, Podiatry, Orthotics/Prosthetics/Pedorthis, Anesthesiology), Surgery (Cardiothoracic Surgery, Colon and Rectal Surgery, General Surgery, Neurosurgery, Plastic Surgery, Vascular Surgery), Primary Care (Family Medicine, Geriatric Medicine, Internal Medicine), Oncology (Oncology, Pediatric Oncology, Radiation Oncology, Surgical Oncology), Specialty Clinics (Allergy/Immunology/Rheumatology, Cardiology, Dermatology, Endocrinology, Infectious Diseases, Nephrology, Neurology, Ophthalmology, Urology, Obstetrics and Gynecology, Transplant).

prevalent among Black patients (22.5%) than White (13.0%) or Asian (12.5%) patients, who did not differ significantly from each other.

For our second objective, we examined the proportion of patients with positive screens who had documented mood disorder diagnoses within the year prior/following the visit at which PRO screens were conducted. Of the 29,314 patients with positive screens, 31.8% ( $n = 9,335$ ) had documented mood disorder diagnoses, while 68.2% ( $n = 19,979$ ) did not (see bottom of **Table 1**). Significant differences emerged regarding likelihood of documented mood disorder diagnoses among those with positive screens as a function of demographics (**Table 2**), with greater likelihood of diagnoses among younger vs. older adults (33.6 vs. 25.2%), female vs. male patients (35 vs. 26.5%), non-White vs. White (35.4 vs. 30.7%), and Hispanic vs. non-Hispanic patients (37.6 vs. 31.6%). Specifically, Asian patients (22.5%) were less likely to have a diagnosis (given a positive screen) than White (30.6%), Black (35.5%), or Other race (37.5%) patients. Other race and Black patients were significantly more likely to have a diagnosis than White patients as well, although did not differ from each other.

Significant differences also emerged regarding likelihood of documented mood disorder diagnoses among those with positive screens as a function of clinical setting where the screen was conducted (**Table 3**), with greater likelihood of diagnoses among those with positive screens in primary care clinics (67.8%) compared with specialty clinics (26.4%) and lower likelihood of diagnoses in orthopedics (23.3%) compared with all other clinics combined (46.8%). To test whether differences by clinical setting were due to differing demographics, we examined age, sex, race, and ethnicity by clinical setting, and found significant results for all comparisons (**Supplementary Table 1**), with the largest differences being greater diversity in race and ethnicity in primary care clinics and older age in oncology clinics. After accounting for these demographic variables (**Table 4**), oncology no longer significantly differed in diagnosis rate among those who screened positive compared to all other clinics. However, even when adjusting for demographic differences, patients screening positive in primary care were 83% less likely to have “missed diagnoses” (i.e., positive screens but no diagnoses) compared to specialty clinics, and patients screening positive in orthopedics were almost three times as likely to be missing diagnoses compared to all other clinics combined.

For our third objective, we examined the association between the three PRO domains. Depression scores were negatively associated with Physical and Social Health ( $r = -0.420$ ,  $r = -0.542$ ,  $p < 0.001$ ). Individuals with positive screens had significantly lower Physical Function and Social Health than those with negative Depression screens (35.60 vs. 44.80 and 39.53 vs. 49.79,  $p < 0.001$ ).

## DISCUSSION

Universal screening for depression is becoming standard of care in many clinical settings. Our results support the utility of universal depression screening for detecting untreated depression across diverse sociodemographic groups and clinical settings. Our results are consistent with prior studies regarding differences in prevalence of clinically significant depressive

**TABLE 2 |** Depression T scores and number of positive screens by demographic groups.

Demographic group	Depression T scores			Positive screens		Diagnoses		Missed diagnoses <sup>b</sup>	
	M (SD)	t (df) or F (df)	95% CI of mean difference <sup>a</sup>	n (% within group)	$\chi^2$ (df)	n (% within group)	$\chi^2$ (df)	n (% within group)	$\chi^2$ (df)
<b>Age group</b>		9.09 (206,466)***	0.36, 0.56		371.51 (1)***		204.82 (1)***		152.07 (1)***
Younger	48.99 (10.16)			23,293 (15.1%)		21,143 (13.7%)		15,478 (66.4%)	
Older	48.53 (9.22)			6,021 (11.6%)		5,803 (11.2%)		4,501 (74.8%)	
<b>Sex</b>		50.98 (206,459)***	2.15, 2.32		668.02 (1)***		2,289.10 (1)***		230.11 (1)***
Female	49.86 (9.84)			18,410 (16.0%)		18,687 (16.2%)		11,963 (65.0%)	
Male	47.63 (9.91)			10,903 (12.0%)		8,256 (9.1%)		8,016 (73.5%)	
<b>Race</b>		911.05 (3,203,603)***	—		2,657.68 (3)***		1,094.68 (3)***		91.37 (3)***
White	48.38 (9.69) <sup>†</sup>			20,961 (12.5%)		20,396 (12.1%)		14,530 (69.3%)	
Black	51.31 (10.62)			5,685 (22.5%)		4,604 (18.2%)		3,666 (64.5%)	
Asian	48.08 (9.71) <sup>†</sup>			374 (13.0%)		231 (8.0%)		290 (77.5%)	
Other	52.05 (11.28)			1,900 (25.9%)		1,476 (20.1%)		1,187 (62.5%)	
<b>Race (binary)</b>					2,376.49 (1)***		816.82 (1)***		58.60 (1)***
White				20,961 (12.5%)		20,396 (12.1%)		14,530 (69.3%)	
Non-White				7,959 (22.4%)		6,311 (17.8%)		5,143 (64.6%)	
<b>Ethnicity</b>		32.09 (197,628)***	3.25, 3.68		1,121.57 (1)***		421.11 (1)***		35.53 (1)***
Not Hispanic	48.74 (9.84)			25,800 (14.2%)		24,326 (12.9%)		17,656 (68.4%)	
Hispanic	52.20 (11.30)			2,328 (26.4%)		1,803 (20.5%)		1,453 (62.4%)	

For ANOVAs, group differences (determined using Bonferroni test) are indicated with superscripts (<sup>†</sup>); groups with same superscripts are not significantly different.

<sup>a</sup>Available for t-tests only.

<sup>b</sup>Sample for these analyses includes positive PROMIS Depression screens only. "Missed diagnosis" refers to those who screened positive but did not receive a mood disorder diagnosis.

\*\*\* $p < 0.001$ .

**TABLE 3 |** Depression mean T scores and number of positive screens by clinic setting.

Clinic comparison	Depression T scores			Positive screens		Diagnoses		Missed diagnoses <sup>a</sup>	
	M (SD)	t (df)	95% CI of mean difference	n (% within group)	$\chi^2$ (df)	n (% within group)	$\chi^2$ (df)	n (% within group)	$\chi^2$ (df)
Primary care vs. specialty		22.67 (53,500)**	1.70 to 2.02		188.04 (1)***		2,948.84 (1)***		1,337.04 (1)***
Primary care	50.37 (9.26)			4,605 (17.0%)		8,073 (29.8%)		1,482 (32.2%)	
Specialty	48.51 (9.67)			3,368 (12.8%)		2,861 (10.8%)		2,480 (73.6%)	
Orthopedics vs. others <sup>b</sup>		19.14 (198,612)**	0.82 to 1.00		66.54 (1)***		3,409.06 (1)***		1,604.10 (1)***
Orthopedics	48.52 (10.02)			18,287 (13.5%)		13,210 (9.8%)		14,033 (76.7%)	
Others	49.43 (9.58)			9,444 (14.9%)		12,147 (19.1%)		5,025 (53.2%)	
Oncology vs. others <sup>b</sup>		0.71 (198,612)	−0.21 to 0.46		11.63 (1)**		7.75 (1)**		5.12 (1)*
Oncology	48.69 (9.42)			406 (12.0%)		380 (11.2%)		300 (73.9%)	
Others	48.81 (9.90)			27,325 (14.0%)		24,977 (12.8%)		18,758 (68.7%)	

<sup>a</sup>Calculated out of positive screens only. "Missed diagnosis" refers to those who screened positive but did not receive a mood disorder diagnosis.

<sup>b</sup>Others includes all other clinics besides the comparison.

\* $p < 0.05$ .

\*\* $p < 0.01$ .

\*\*\* $p < 0.001$ .

symptoms across sociodemographic groups, with a greater number of positive depression screens among younger adults, women, non-White patients (particularly Black and Other race patients), and Hispanic adults. These same sociodemographic indicators are also associated with greater likelihood of a documented mood disorder diagnosis in the medical record around the time of screening for those with positive screens (i.e., whether depression may have been detected and treated).

Regarding racial/ethnic differences in scores on the PROMIS depression screen, our results are consistent with some studies using the PHQ-9 indicating greater depression severity among racial/ethnic minorities. It may be that depressive symptom severity is higher among racial/ethnic minorities presenting to medical settings than in community-based, nationally representative samples. At the same time, these differences may reflect findings from other studies that indicate that although prevalence of Major Depressive Disorder may be lower among racial/ethnic minorities, disease burden (e.g., longer chronicity of disease) may be greater for racial/minorities (15, 22). Our results also point to the need for more fine-grained (and patient-centered) assessments of race and ethnicity given our finding for high rates of positive screens among those of "Other races." Overall, our results suggest an opportunity to reduce health disparities in depression treatment given that a greater number of patients without documented mood disorders were detected by universal screening in groups with known health disparities in depression care.

Our results also indicate differences across clinical settings with regards to likelihood of detection of depression (and presumably treatment) among those with positive screens. After adjusting for demographic differences in clinical settings, patients screened in primary care were most likely to have received mood disorder diagnoses around the time of screening, indicating potential depression treatment within the healthcare system. These results could indicate that primary care clinicians were most likely to provide depression-focused care in response to universal screening or that depression had already been detected and treated for patients with positive screens in primary care. There are several reasons this might be the case. First, it is possible that patients in primary care were more likely to complete follow-up screens (with repeated positive screens), which we were unable to examine in this paper; this interpretation would be consistent with providers using a "watchful waiting" management approach (23). Second, it is possible that patients are more honest in rating their depression symptoms in a primary care setting where they may already have a trusted relationship with a physician who is trained to assess and attend to biopsychosocial needs, and/or has additional resources to do so (e.g., embedded mental health providers) (24). Third, patients seen in specialty clinics who do not have a primary care physician in the same health system have less complete data in the EMR: PCPs will often document a broader variety of health problems and concerns (than specialty providers) and also refer for specialty care within their healthcare network. Providers in specialty clinics may not document depression care if it is not seen as relevant to the patient's presenting problem; thus our data for specialty clinics may be less complete compared to primary care. Future

**TABLE 4 |** Depression mean T scores and number of positive screens by clinic setting, adjusting for demographics.

Models	Depression T scores <sup>b</sup>		Positive screens			Diagnoses			Missed diagnoses <sup>c</sup>		
	F (df)	Partial $\eta^2$	Step $\chi^2$ (df) <sup>a</sup>	Odds ratio	95% CI	Step $\chi^2$ (df) <sup>a</sup>	Odds ratio	95% CI	Step $\chi^2$ (df) <sup>a</sup>	Odds ratio	95% CI
Primary care vs. specialty <sup>d</sup>	222.40 (149,925)	0.004	52.43 (1)	1.22	1.16–1.29	2,453.75 (1)***	3.45	3.27–3.63	1,166.11 (1)***	0.17	0.15–0.19
Orthopedics vs. others	76.90 (1,189,369)***	0.000	3.25 (1)	1.03	1.00–1.06	2,633.34 (1)***	0.48	0.46–0.49	1,457.96 (1)***	2.91	2.75–3.07
Oncology vs. others	13.60 (1,189,369)***	0.000	0.01 (1)	1.01	0.90–1.13	6.60 (1)**	1.16	1.04–1.30	0.001 (1)	1.00	0.79–1.26

All models are controlling/covarying Age Group, Sex, Race, and Ethnicity.

<sup>a</sup>In logistic regressions, demographic covariates were entered in Step 1, and clinic comparison was entered in Step 2. Chi square statistics for the addition of Step 2 (i.e., addition of the clinic comparison) are reported.

<sup>b</sup>Estimated marginal mean T scores were higher in Primary Care ( $M = 50.15$ ,  $SE = .06$ ) vs. Specialty Clinics ( $M = 48.80$ ,  $SE = 0.06$ ), lower in Orthopedics ( $M = 48.59$ ,  $SE = 0.02$ ) vs. Others ( $M = 49.12$ ,  $SE = 0.04$ ), and higher in Oncology ( $M = 49.47$ ,  $SE = 0.18$ ) vs. Others ( $M = 48.82$ ,  $SE = 0.02$ ).

<sup>c</sup>Calculated out of positive screens only. "Missed diagnosis" refers to those who screened positive but did not receive a mood disorder diagnosis.

<sup>d</sup>Comparison group is Specialty Clinics.

\*\* $p < 0.01$ .

\*\*\* $p < 0.001$ .

research examining whether patients receive primary care in a different health system as well as research specifically examining provider behavior in response to depression screening, and how it varies by specialty, training and practice-level mental health resources, could address this issue. Visit recordings of clinician-patient communication around screening results (25) as well as patient feedback on provider communication (26) can be used to inform best practices and procedures for maximizing utility of universal depression screening tailored to the needs of clinical settings. Examining provider behavior in response to alerts provided in the EMR in response to elevated PRO scores could also provide clues as to how screens are responded to and also suggest strategies to address unmet biopsychosocial needs, such as health-system support for care managers to follow-up on PRO scores and digital health programming for depression self-management.

Our results regarding sociodemographic differences may indicate disparities in diagnosis (and potentially treatment) among patients with significant symptoms (i.e., under-detection) but could also indicate differences in the accuracy of the PROMIS measure in detecting clinically significant symptoms across diverse groups. For example, positive screens were less common among older (vs. younger) adults and, given a positive screen, older adults were less likely to receive a depression diagnosis. Given differing symptom profiles for depression in older adults, it is possible that age-specific norms could more accurately identify clinically-relevant depressive symptoms in this population by using older adults as the reference population. The utility of sex and race/ethnicity-specific norms could also be explored. Future work is needed to better understand the nature of discordant screens/diagnoses (i.e., positive screen/absent diagnosis and negative screen/positive diagnosis), including confirming whether treatment was considered but not provided because it was not needed or not desired by patients; whether further assessment was conducted to evaluate the need for treatment; and what specific treatment options were considered, provided, and received (e.g., antidepressant medications, referral to psychiatry clinics). Given associations

of depression scores with physical and social health, future work is also needed to examine whether administering brief biopsychosocial PRO assessments with physical, psychological, and social domains might most accurately identify patients with untreated depression and other unmet health needs. For example, for some patients, depression may manifest with more physical or social health challenges than psychological or emotional symptoms (27, 28). Supplementing depression screens—that capture psychological health—with physical function and social health screens may have additional benefits beyond depression care, to address more fully a patient's biopsychosocial health profile that may impact numerous domains of function, symptoms, behaviors, and feelings.

Limitations of our study include that the demographic breakdown of our sample is representative of the settings in which PROs were rolled out, with unclear generalizability to the medical center more broadly. Future work is needed to study processes and results from wider implementation of PROs to maximize diversity of settings and patients and reduce potential health disparities in depression screening and care. In addition, our analyses by clinic setting should be considered in light of the high representation of patients seen in orthopedic clinics given that these clinics were the first to initiate depression screening. Second, differences in depression by race may be due to intersectionality with ethnicity, as a majority of "Other race" patients also identified as Hispanic (62.9%). Findings on ethnicity may not be generalizable to other regions of the United States, as Hispanics in the current study region are mostly of Puerto Rican origin (~70%). Puerto Ricans have been identified as having higher rates of depression compared to other Hispanic subgroups (29). Hispanics in the United States are more likely to be of Mexican origin (~60%) (30). Thus, future work should examine racial/ethnic disparities in depression screening and diagnosis in other regions. Third, we only examined depression screens at one point in time (i.e., the first depression screen completed by a patient), whereas some patients may have completed depression screens several times over the study period; this could mean that some patients were mis-classified in our study—specifically



those we classified as false negative screens (i.e., negative screen, positive diagnosis). Fourth, we used the presence of a mood disorder diagnosis as a proxy for potential assessment and treatment of depression, which is a limited indicator and should be validated in future studies regarding its accuracy given the ease of assessing this variable in the EMR. Finally, only some of the patients in our sample completed PROs for physical and social function, thereby limiting our ability to examine benefits of universal screening with biopsychosocial PROs.

Our results indicate that universal screening for depression symptoms with PRO screens appears acceptable and has the potential to be clinically useful in detecting depression in diverse patient populations outside of behavioral health in a large medical center. However, other research has failed to document improved mental health outcomes in response to universal depression screening in primary care (31). Expanded delivery of PROs to include physical and social functioning as well as depression should be explored as to whether such a strategy produces beneficial outcomes; in particular, such an approach could be used to develop a clinically-relevant model for addressing patients' biological, psychological, and social needs in an integrated fashion across the health system. For example, while one patient may present for care in an orthopedic clinic, another in the Emergency Department, and other in primary care, a population-health approach that helps patients and clinicians address physical, psychological, and social health can promote person-centered and cost-effective care by sharing responsibility for these dimensions of health across the health system. Brief PRO screens, such as computerized adaptive tests (that are grounded in Item Response Theory) in the PROMIS self-report measures may be especially useful for this type of strategy because these measures each take < 1 min to complete on average (low patient burden) but have strong psychometric properties and clinical norms to aid in interpretation. This type of health system strategy would be most effective if clinicians were prompted to communicate about biopsychosocial concerns and linkages could be made to connect patients with biopsychosocially-relevant resources in the health system and the community. Approaches might include behavioral interventions to promote improved patient-provider communication about life stressors and unmet social needs that can capitalize on digital health technologies, such as a tablet-based intervention that was shown to increase patient disclosure of unmet social needs in healthcare appointments (32, 33). Another approach could be "social prescribing" strategies, whereby medical providers "prescribe" social and wellness programs in the community, such as volunteering and social

programs (34, 35). Given acceptability and utility of universal depression screening in detecting untreated depression, a next step could include a brief biopsychosocial PRO assessments delivered across settings in order to form the foundation of a person-centered, population-health management strategy for large health systems that will promote patient engagement in care, optimal healthcare utilization, and improved health.

## DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because these data were produced as part of routine clinical care and cannot be shared outside our institution without a data use agreement. Requests to access the datasets should be directed to Kimberly A. Van Orden, [kimberly\\_vanorden@urmc.rochester.edu](mailto:kimberly_vanorden@urmc.rochester.edu).

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Rochester, Research Subjects Review Board. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

## AUTHOR CONTRIBUTIONS

KV, KC, MH, and MW contributed to conception and design of the study. KF and AL organized the database. JL and CS performed the statistical analysis. KV and JL wrote the first draft of the manuscript. CS, KF, and MW wrote sections of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

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## SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpsy.2021.796499/full#supplementary-material>

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# The Effectiveness of a Community Psychiatric Rehabilitation Program Led by Laypeople in China: A Randomized Controlled Pilot Study

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**Background:** Community psychiatric rehabilitation has proven effective in supporting individuals and their families in recovering from mental illness. The delivery of evidence-based community rehabilitation services, however, requires health care workers to possess a set of specially trained knowledge and skills. Most developing countries, including China, do not have specially trained mental health personnel. The purpose of this study was to test the feasibility and efficacy of a community psychiatric rehabilitation program delivered by laypeople.

**Method:** We conducted a randomized controlled study. Patients at two sites in Chengdu, China, were randomly assigned to either the laypeople-delivered (LPD) community psychiatric rehabilitation group ( $N = 49$ ) or the drop-in center control group ( $N = 45$ ). The outcomes were changes in symptoms, social functioning, and family functioning over 6 months, as measured by the Positive and Negative Syndrome Scale (PANSS), the Personal and Social Performance Scale (PSP), the Family Burden Scale of Disease (FBS), and the Family APGAR index.

**Results:** The number of sessions received over the 12-week period of treatment ranged from 20 to 100%, with a mean completion rate of 77.32% for all 12 sessions. Statistically significant interactions between group and time were found for the total PANSS [ $F_{(2, 94)} = 12.51, p < 0.001$ ] and both the Negative PANSS [ $F_{(2, 94)} = 5.89, p < 0.01$ ] and Positive PANSS [ $F_{(2, 94)} = 6.65, p < 0.01$ ] as well as the PSP [ $F_{(2, 94)} = 3.34, p < 0.05$ ], FBS [ $F_{(2, 94)} = 5.10, p < 0.01$ ], and Family APGAR index [ $F_{(2, 94)} = 4.58, p < 0.01$ ]. The results showed that the experimental group outperformed their counterparts in symptom management, personal social functioning, family care burden, and coherence.

**Conclusion:** These results support the feasibility and efficacy of having laypeople deliver psychiatric rehabilitation services. A discussion and limitations of the study have been included.

**Keywords:** community-based, psychiatric rehabilitation, multidisciplinary teams, mental illness, randomized-control

## INTRODUCTION

Psychiatric rehabilitation, also known as psychosocial rehabilitation, has changed service delivery for people with severe and persistent mental illness. It catalyzed the deinstitutionalization movement in America in the early 1970s, moving psychiatric treatment from institution based to community based. With accumulating evidence, community psychiatric rehabilitation has become the main service delivery model. However, in Asia, due to a lack of resources and specialized trained rehabilitation professionals, community psychiatric rehabilitation is still in the early stages of development (1, 2). Tse, Huang, and Zhu (2), in addressing Asian mental health care reforms, pointed out that China has a population of 1.3 billion, with an estimate of 173 million Chinese citizens suffering from diagnosable mental disorders, of whom 158 million have never received any treatment (3). Approximately 16 million Chinese citizens have severe mental illness, and this figure is expected to grow. Most of these individuals go without treatment due to a lack of community rehabilitation resources (4). The insufficient number of mental health professionals exacerbates mental health care problems. Presently, China has only 4,000 fully qualified, licensed psychiatrists (5) and has few professionally trained allied health workers, such as rehabilitation counselors, social workers, occupational therapists, and rehabilitation psychologists, to work with people with severe persistent mental illness.

*In Asian countries, about 70% of clients with schizophrenia live with their family. The unpredictable and bizarre behaviors of the patients, stressors of stigma upon the family, and family conflicts in the caring process have greatly impacted the daily lives of caregivers. Meanwhile, the preparation and knowledge about disorders of caregivers might influence the client outcome (6). Community psychiatric rehabilitation has proven effective in supporting individuals and their families recovering from mental illness (6–9).*

In many Western countries, clinical and social services for people with schizophrenia are coordinated by specialist community-based multidisciplinary teams. However, such specialist services are not presently feasible in low-income and developing countries because of serious human and financial resource constraints. Hence, the development of alternative methods for the provision of accessible, community-based services for people with schizophrenia within these countries is a global public health priority (10). In most developing countries, including China, alternative methods are needed for the provision of community-based psychiatric rehabilitation. “Task sharing” (11), a widely adopted strategy, has been used by developing countries to address the shortage of qualified mental health workers. The strategy uses lay health workers with appropriate training and supervision to provide access to evidence-based mental health care interventions. Thus, the current pilot study sought to accomplish two goals. The primary aim of the study was to assess the feasibility of a laypeople-delivered (LPD) community psychiatric rehabilitation program. The second goal was to assess whether the LPD community psychiatric rehabilitation program confers greater benefit than

the control condition for the patient’s social functioning and the family’s psychological well-being.

## METHODS

### Design

We used a randomized controlled design to compare the efficacy of LPD community psychiatric rehabilitation to that of a community drop-in center control group. Participants were randomized to receive either LPD community psychiatric rehabilitation (a 12-week program) or drop-in center services (control group). Assessments were conducted at baseline, posttreatment (3 months), and follow-up (6 months) by trained research assistants.

### Participants

This study was approved by the research ethics committee of West China Hospital of Sichuan University, written informed consent was obtained from the parents/guardians of all participants, and consent was obtained from the study participants prior to participation. Participants were recruited from two different organizations in Chengdu, a major city in Sichuan, China. The West China Hospital Mental Health Center, a major mental hospital in Chengdu, provided a list of possible participants who had been discharged from the hospital from August 1, 2012, to July 31, 2014. The Yulin Community Health Center provided a list of residents in the community who had a diagnosis of mental disorders. Each potential participant was interviewed with the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (SCID), for their eligibility for the study by psychiatrists or graduate students who were trained in SCID. After informed consent was obtained from each eligible participant, the participants were randomly assigned to either the LPD community psychiatric rehabilitation group or the drop-in center control group, and a baseline assessment was conducted.

G\*Power 3.1 was used to calculate the required sample size with an effect size of 0.25 (medium), alpha error probability of 0.05, and power of 0.80. For repeated-measures ANOVAs with between- and within-group interactions, the required sample size was 62. In view of possible dropouts and incomplete attendance of the program, we recruited 108 participants with a major diagnosis of schizophrenia for the study. Admission criteria for the study included (1) having a diagnosis of schizophrenia or schizoaffective disorder; (2) being between 16 and 60 years of age; and (3) not having a diagnosis of mental incompetence or organic brain syndrome or a primary diagnosis of substance dependence.

We used SPSS software to randomize the participants; 58 participants from 108 participants were randomly assigned to the LPD group. Ninety-four participants completed the entire course of the study. Nine participants, seven due to <25% attendance and two due to refusal, dropped out of the LPD community psychiatric rehabilitation group, and five participants from the control group refused to continue in the study due to transportation problems. The dropouts did not differ from the rest of the sample in terms of characteristics or functions. Thus,



the LPD community psychiatric rehabilitation group consisted of 49 participants, and the control group had 45 participants.

## Assessment Measures

### Psychiatric Symptom Severity

A Chinese version of the PANSS (12) was used to measure psychiatric symptom severity. It is a structured clinical interview consisting of 30 items designed to assess the severity of symptoms over the past week on a 7-point scale (1 = absent to 7 = extreme); higher scores indicate more severe symptoms. The PANSS raters were trained to an interrater agreement of 80% on a series of videotapes for which “gold standard” consensus ratings had been determined by a group of experienced raters. The PANSS subscales were used to measure negative symptoms, positive symptoms, and dysphoric mood. The reported psychometric properties of the PANSS include Cronbach's alpha coefficients of 0.73 on the positive scale, 0.83 on the negative scale, and 0.87 on the general psychopathology scale.

### Social Functioning

A Chinese version of the Personal and Social Performance Scale (PSP) (13) was used to assess the participant's social functioning. The PSP was developed based on the social functioning component of the DSM-IV social and occupational functioning assessment scale (SOFAS). The scale assesses four main areas of social functioning: socially useful activities; personal and social relationships; self-care; and disturbing and aggressive behaviors. Difficulty in each area is rated on a six-point scale (absent, mild, manifest, marked, severe, or very severe), with lower ratings indicating better social functioning. A global item ranging from 1 to 100 in 10-point intervals is rated by the interviewer, where lower scores indicate worse functioning. Cronbach's alpha of 0.84 was reported.

### Family Functioning

A Chinese version of the FBS was used to assess the family burden (14). The FBS has 24 items spread across six factors: economic burden, impact on daily activities, impact on social life, impact on free time, impact on physical health, and impact on mental health. The ratings of 24 items are made with a three-level scale from 0 to 2, with higher scores indicating a greater burden. Cronbach's alpha coefficient was 0.87, and split-half reliability was 0.94 for FBS.

A Chinese version of the Family APGAR index was used to measure family function (15). The Family APGAR scale scores five dimensions of family function: adaptability, partnership, growth, affection, and resolution. The scores of the scale assess overall satisfaction with family life and provide a composite measure of perceived family functioning. The total score ranges from 0 to 20. The higher the score, the higher the level of perceived family function. Cronbach's alpha of 0.86 was reported.

## Treatments

### Development of the LPD Community Psychiatric Rehabilitation Program

Several strategies were used in the development of the LPD community psychiatric rehabilitation program, namely,

literature review, expert consultation, and group discussion. Through an extensive literature review, we have identified several models that would be relevant to the current pilot project. These models include illness management and recovery (7), case management (16), psychosocial rehabilitation (17), and family psychoeducation (18, 19). With input from our consultant (CL) and several discussion meetings among the community psychiatric rehabilitation team members (the authors of the article), the structure and contents of the LPD community psychiatric rehabilitation program were formed. Underlying practice principles of our LPD community psychiatric rehabilitation program were drawn from several lines of behavioral science research, which found that people are more apt to change when they are in the context of a positive relationship, when they set their own goals, are taught skills, receive support, have positive expectations or hope for the future and when they believe in their self-efficacy (9, 17, 20). All of these change elements demonstrated in the behavioral science research literature became critical ingredients for the LPD community psychiatric rehabilitation services.

With these guiding principles, we identified core components of the LPD community psychiatric rehabilitation program. These core components include psychoeducation provided to the patients and their families (about mental illness, its treatment, and recovery), medication management (using cognitive-behavioral approaches to enhance medication adherence), case management (developing a SMART goal-oriented recovery plan), social skills training (strengthening social support and community reintegration), stress management training (for the management of stress and persistent symptoms), coping and problem solving training (using counseling, cognitive-behavioral therapy [CBT], and problem-solving skills to deal with personal issues and problems that would interfere with the recovery plan). **Table 1** outlines the modules and contents of the LPD community psychiatric rehabilitation program.

### Treatment Protocol

**Figure 1** shows the flowchart of this study. After randomization, the experimental group attended the LPD community psychiatric rehabilitation program modules, as shown in **Table 1**. The module contents were converted to PowerPoint to assist in the group-based delivery of the curriculum. Every session had the same routine, which meant that the whole program followed a structured pattern. Each module was led by two community lay psychiatric worker (CLPW) instructors who were trained on how to deliver the module curriculum. A combination of educational, motivational, and cognitive-behavioral teaching strategies and homework assignments was used in the delivery of the module. Each session lasted 60 min, meeting once a week. For the family psychoeducation module, both the patients and their family members participated in the session. This group could provide an opportunity to review the fundamentals of illness management with concerned others in a context where clients could obtain support and help in pursuing their personal recovery goals. The module was conducted following the Substance Abuse and Mental Health Services Administration (SAMHSA) guidelines.

**TABLE 1** | Overview of the topics for the LPD community psychiatric rehabilitation program modules.

Module	Topic	Goals	# of 60-min sessions
1	Facts about mental illnesses	<ul style="list-style-type: none"> <li>• Etiology of schizophrenia, a brain disease</li> <li>• Identify symptoms associated with schizophrenia</li> <li>• Dispel myths about schizophrenia</li> <li>• Address stigma, public and self stigmas</li> </ul>	2
2	Family psychoeducation	<ul style="list-style-type: none"> <li>• Education about serious mental illnesses</li> <li>• Information resources, especially during periods of crises</li> <li>• Skills training and ongoing guidance about managing mental illnesses</li> <li>• Problem solving</li> <li>• Social and emotional support</li> </ul>	8
3	Recovery and rehabilitation	<ul style="list-style-type: none"> <li>• Understand the process of recovery and rehabilitation</li> <li>• Increase awareness of recovery</li> <li>• Help clients become aware of people with schizophrenia who lead productive lives</li> </ul>	2
4	Medication management	<ul style="list-style-type: none"> <li>• Discuss benefits and side effects of medications</li> <li>• Help clients weigh the pros and cons of taking medications</li> <li>• Teach behavioral skills tailored to facilitate medication adherence</li> </ul>	4
5	Social skills training	<ul style="list-style-type: none"> <li>• Basic conversation skills and getting closer to people, making eye contact, starting and ending a conversation, making and refusing requests, expressing opinions to others, and showing appropriate emotions</li> <li>• Working on correcting deficits in receptive, processing, and sending social skills</li> <li>• Teach strategies for increasing support, such as making friends and finding places to meet people</li> <li>• Discuss how building social support can facilitate recovery</li> </ul>	8
5	Stress management	<ul style="list-style-type: none"> <li>• Explain that stress and biological vulnerability causes the symptoms of schizophrenia</li> <li>• Discuss strategies for reducing stress and biological vulnerability</li> <li>• The relationship between stress thoughts (automatic negative thoughts), emotions and behavior, cognitive restructuring and mindfulness, and relaxation and breathing techniques</li> <li>• Healthy and unhealthy stress coping methods</li> </ul>	8
6	Case management	<ul style="list-style-type: none"> <li>• Set personal recovery goals</li> <li>• Develop SMART goals</li> <li>• Help consumers and families problem-solve issues related to the treatment plan</li> <li>• Case review and modification</li> </ul>	12
7	Coping and problem solving	<ul style="list-style-type: none"> <li>• Teach the patient to cope with problems and persistent symptoms</li> <li>• Teach a problem-solving model</li> <li>• Help clients identify common problems and symptoms that cause distress</li> <li>• Practice coping strategies for persistent symptoms</li> </ul>	8

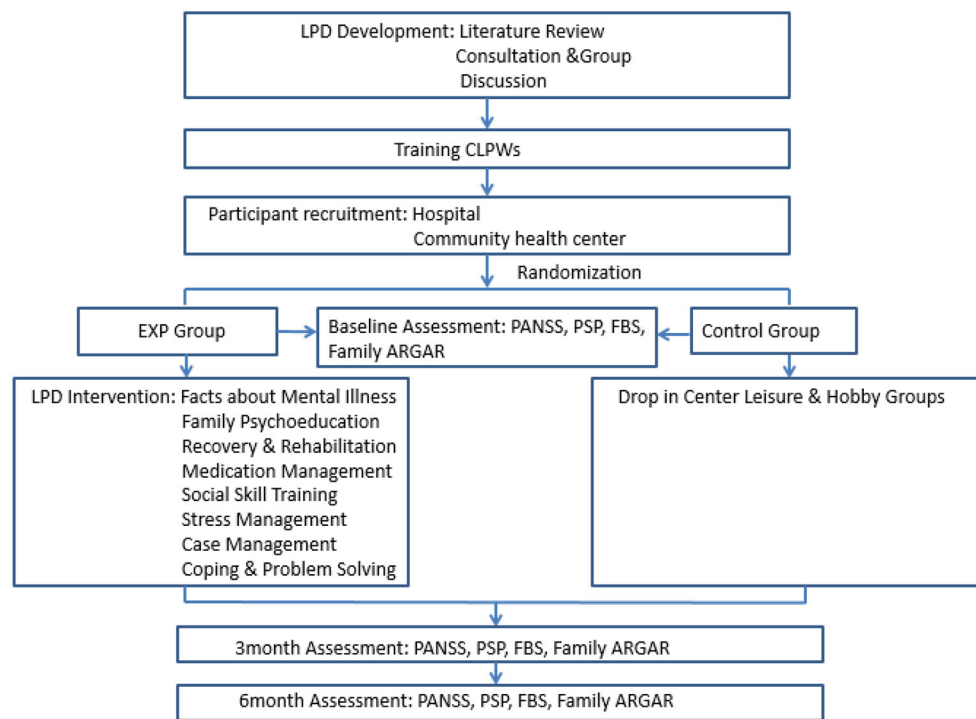
The case management module was conducted on an individual basis. This module lasted 12 weeks. Each case manager had three to five cases depending on the difficulties of the cases and the availability of the case manager. There were 15 CLPW case managers involved in the study. In addition to working with the participant, the case manager also worked with the family to help participants learn self-management strategies and pursue their personal goals. In case management, the participant's individual goals were often broken down into smaller steps to facilitate continuous progress toward achieving the goals.

### Drop-in Center Control Group

The drop-in center, a part of the community psychiatric rehabilitation program, provided a place for participants to get together to engage in various leisure and hobby activities, such as singing, painting, listening to music, arts and crafts, and local outings. It was available to both experimental and control group participants. The drop-in center opened 3 days a week to the community from 9:00 a.m. to 4:00 p.m., and attendance was voluntary.

### Training of Lay People in Community Psychiatric Rehabilitation

CLPWs were recruited locally from the West China Hospital Mental Health Center and local volunteer organizations. CLPWs must have completed high school education, preferably with a college degree and with no prior or little training in mental health or psychiatric rehabilitation. We recruited 12 CLPWs from community volunteer organizations. Many of them had served as disaster volunteers during the 2008 earthquake in Sichuan. Fifteen nurses from the West China Hospital Mental Health Center who had no formal training in psychiatric rehabilitation also served as CLPWs. All CLPWs were women with an average of 14.6 years of education. Half of the CLPWs had basic counseling skills training through the 2008 earthquake relief project. The CLPWs were responsible for delivering the community psychiatric rehabilitation program. Psychiatric professionals (two psychologists from the United States, two psychiatrists from China, and one occupational therapist from Hong Kong) supervised the CLPWs and were responsible for the overall development and implementation of the intervention.



**FIGURE 1** | Flowchart of the study (LPD psychiatric rehabilitation program).

Under the leadership of the second author (CL), the psychiatric rehabilitation team developed a training curriculum based on the community psychiatric rehabilitation program topics and contents. The CLPW training program was 3 months long. Experts and professionals in psychiatric rehabilitation from overseas, including the United States, Hong Kong, and Singapore, conducted the training. Depending on the content of the modules, a knowledge-based curriculum required 4–8 h of didactic training. Modules on skill-based training, such as social skills, stress management, counseling and cognitive behavioral therapy skills, and case management skills, involve hands-on practice, role playing, and supervision. Each of the skills training modules required 8–16 h. In addition to module training, all case managers received weekly face-to-face or Skype supervision for an hour from the supervising professionals. Competence of the CLPWs was established through observation and the demonstration of content knowledge and skills. All CLPWs met the minimum level of competence.

*During the trial, we kept the research and intervention teams physically separate.*

### Drug Interventions

Both participants of two groups visited the psychiatric clinic on a regular basis, every 1–3 months a time. *Psychiatric clinics mainly offer drug intervention, and psychiatrists adjust the dose of antipsychotics according to the severity of the patient's symptoms. Family members of 80% of patients will accompany them to the*

*visit. Medical insurance reimbursed 90% of the patients' medical expenses, and the community subsidy is 1,500 yuan a year.*

### Statistical Analyses

To test the between- and within-group differences, we used repeated-measures ANOVAs on data from baseline, 3 months, and 6 months and complemented these analyses with traditional significance testing. Follow-up analyses were conducted for interaction effects. Effect sizes of the comparisons were reported. The Mauchly sphericity criterion ( $W$ ) was used to judge the validity of the conditions for repeated-measures ANOVAs, and the conditions were met. Multiple stepwise regression models were used to identify the predictor of gaining benefit from the LPD program (**Supplementary Materials**, statistical analysis).

## RESULTS

### Sample Characteristics

Demographic characteristics and baseline measures are presented in **Table 2**. Most of the participants had a diagnosis of schizophrenia, and 2% had a diagnosis of schizoaffective disorder. Participants had a mean age of 28.80 years ( $SD = 10.55$ ) with an onset age of 20.79 ( $SD = 6.14$ ). Participants were more likely to be male (59%) and had a mean education level of 12.17 years ( $SD = 2.70$ ). No significant differences were found in any of the sociodemographic variables between the two groups.

**TABLE 2 |** Sample characteristics, total sample.

Variables	LPD psychiatric rehabilitation (N = 49)		Drop-in center control (N = 45)		t/ $\chi^2$ /z/F	p
	N	%	N	%		
Age (M $\pm$ SD)	29.68 $\pm$ 10.81		27.71 $\pm$ 10.24		0.931	0.354
Gender						
Male	31	55	28	62	0.484	0.545
Female	25	45	17	38		
Diagnosis						
Schizophrenia	55	98	44	98	2.064	0.154
Schizoaffective	1	2	1	2		
Age of onset (M $\pm$ SD)	21.23 $\pm$ 6.55		20.24 $\pm$ 5.63		0.802	0.425
Duration of illness (mean rank)	52.11		49.62		-0.426	0.67
Number of episodes (mean rank)	52.02		49.73		-0.4	-0.768
Number of hospitalizations (mean rank)	49.08		53.39		0.69	0.443
PANSS <sup>a</sup> (M $\pm$ SD)	57.86 $\pm$ 13.92		53.11 $\pm$ 14.12		-1.692	0.094
PSP <sup>b</sup> (M $\pm$ SD)	59.64 $\pm$ 16.29		64.22 $\pm$ 16.17		1.409	0.162

<sup>a</sup>PANSS, Positive and Negative Syndrome Scale (possible scores range from 30 to 210, with higher scores indicating more severe symptoms).

<sup>b</sup>PSP, Personal and Social Performance Scale (possible scores range from 1 to 100, with lower scores indicating poorer functioning).

## Treatment Participation

The LPD psychiatric rehabilitation group: the number of sessions attended over the 12-week period of treatment ranged from 20–100%, with a mean completion rate of 77.32% for all 12 sessions. Among the participants who completed the baseline assessment, seven participants attended <25% of the program and were considered dropouts and excluded from the analyses.

The drop-in center control group: the participants of the drop-in center attended 6.38  $\pm$  4.36 (1–25) times within the 3 months it was open.

## Evaluation of Treatment Efficacy

Table 3 provides a summary of the mean differences and levels of significance associated with the primary outcome measures from pretreatment to posttreatment. Repeated-measures analyses of variance were conducted to examine the impact of the LPD community psychiatric program with group (intervention vs. control) as the independent variable and assessment point (pretest, 3-month test, or 6-month test) as time. For these analyses, the group-by-time interaction tests whether participants in the LPD community psychiatric program improved more than clients in the drop-in center control group. An analysis was performed for each of the outcome measures, including the two subscales of the PANSS, PSP, FBS, and Family APGAR. Statistically significant interactions between group and time were found for the total PANSS [ $F_{(2,94)} = 12.51, p < 0.001$ ] and both the Negative PANSS [ $F_{(2,94)} = 5.89, p < 0.01$ ] and Positive PANSS [ $F_{(2,94)} = 6.65, p < 0.01$ ] as well as the PSP [ $F_{(2,94)} = 3.34, p < 0.05$ ], FBS [ $F_{(2,94)} = 5.10, p < 0.01$ ], and Family APGAR [ $F_{(2,94)} = 4.58, p < 0.01$ ].

The means and standard deviations in Table 3 indicate the source of these interactions. The data in the table indicate that the participants' psychiatric symptoms and personal social skills improved significantly more for participants in the LPD psychiatric rehabilitation program than for those who received

drop-in center service. Similarly, family care burden and family function improved significantly more for the LPD psychiatric rehabilitation program group than for the drop-in center control group. Figure 2 shows the interaction effects.

## DISCUSSION

The pilot data on the implementation of the LPD community psychiatric rehabilitation program support both its feasibility and efficacy. Changes from baseline to posttreatment and to follow-up indicated significant effects across symptom management, personal social functioning, family care burden, and coherence, with interactions between treatment modality (experimental vs. control groups) and change over time. Our findings support the premise that the LPD community psychiatric rehabilitation program not only provides information but also helps consumers improve their social relationships and cope more effectively with their symptoms. Families also benefit from consumers' participation in the rehabilitation program.

This study found that compared with their control counterparts, persons who participated in the LPD community psychiatric rehabilitation program showed significant improvement in their psychiatric symptoms and social functioning. The specific treatment elements in the LPD program, such as case management, family psychoeducation, and medication management, have been proven effective in significantly reducing psychotic symptomatology in previous studies for both first-episode and chronic populations of schizophrenia (7, 10, 16, 21). These findings may be due to closer monitoring of symptoms in integrated treatment to improve adherence to medication. Social skills training and stress management can improve the ability of patients to cope with stressors, which can help patients cope with their challenges of living in the community (21).



**TABLE 3 |** Means (standard deviations) and effect sizes for outcome variables for each treatment group before and after the intervention.

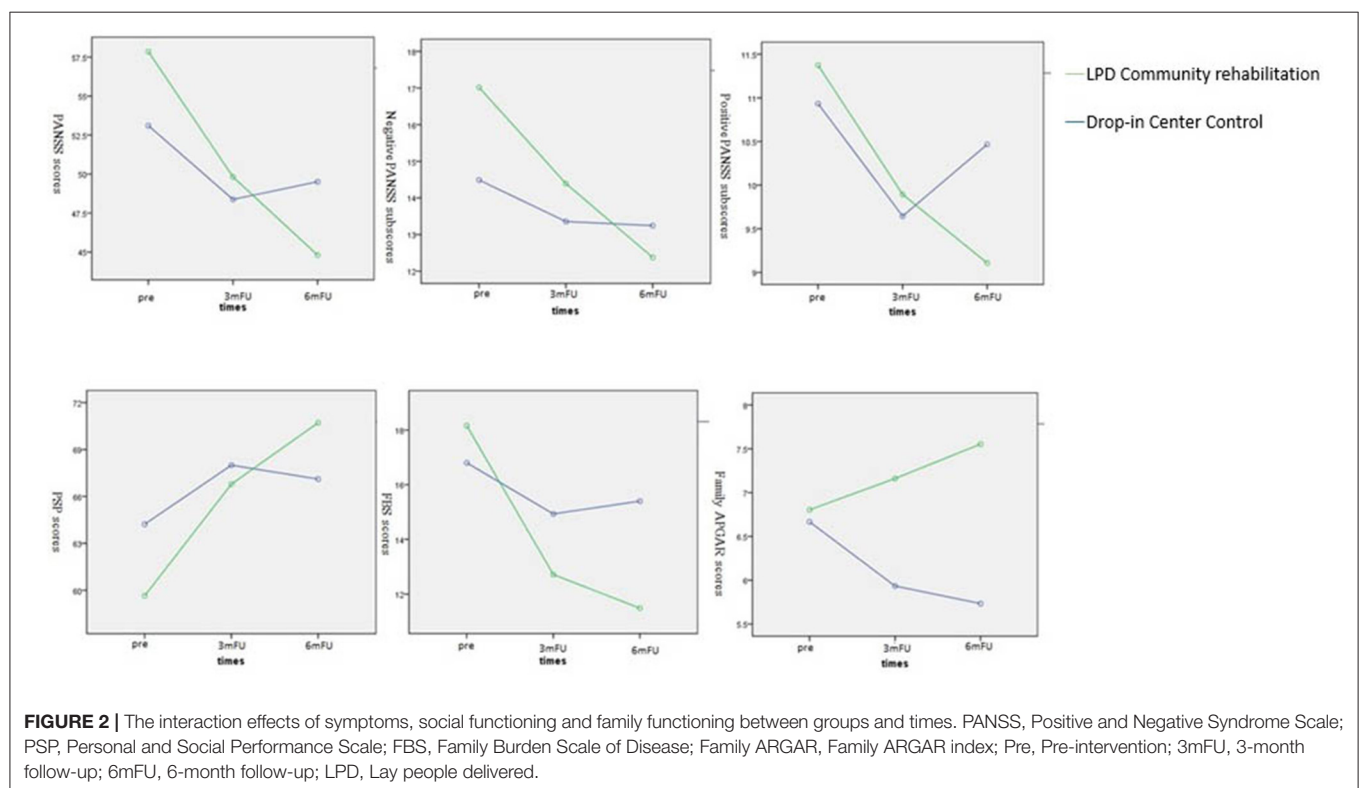
Variables	LPD community rehabilitation (N = 49)			Drop-in center control (N = 45)			group × time	
	Preintervention	3-month follow-up	6-month follow-up	Preintervention	3-month follow-up	6-month follow-up	F	p
	M ± SD	M ± SD	M ± SD	M ± SD	M ± SD	M ± SD		
PANSS <sup>a</sup>	57.86 ± 13.92	49.82 ± 11.09	44.80 ± 10.72	53.11 ± 14.12	48.38 ± 13.99	49.51 ± 16.12	12.51	0.001
Negative PANSS	17.02 ± 7.42	14.39 ± 5.48	12.37 ± 4.75	14.49 ± 6.36	13.36 ± 5.96	13.24 ± 5.99	5.89	0.004
Positive PANSS	11.38 ± 4.03	9.89 ± 3.36	9.11 ± 2.67	10.93 ± 3.95	9.64 ± 3.57	10.47 ± 4.35	6.65	0.002
PSP <sup>b</sup>	59.64 ± 16.29	66.79 ± 12.52	70.71 ± 14.12	64.22 ± 16.17	68.00 ± 19.49	67.11 ± 17.53	3.34	0.039
FBS <sup>c</sup>	18.16 ± 7.55	12.71 ± 6.24	11.48 ± 7.76	16.80 ± 10.39	14.93 ± 10.23	15.40 ± 11.11	5.10	0.008
Family APGAR <sup>d</sup>	6.80 ± 2.42	7.16 ± 2.63	7.55 ± 2.49	6.67 ± 2.52	5.93 ± 3.60	5.73 ± 3.73	4.58	0.013

<sup>a</sup>PANSS, Positive and Negative Syndrome Scale (possible scores range from 30 to 210, with higher scores indicating more severe symptoms).

<sup>b</sup>PSP, Personal and Social Performance Scale (possible scores range from 1 to 100, with lower scores indicating worse functioning).

<sup>c</sup>FBS, Family Burden Scale of Disease (possible scores range from 0 to 48, with higher scores indicating more burdens).

<sup>d</sup>Family APGAR, Family APGAR index (possible scores range from 0 to 20, with higher scores indicating a higher level of perceived family function).



The family of the experimental group also showed less family burden and better family function in adaptability, partnership, growth, affection, and resolution. A previous family psychoeducation program for psychosis patients and their families in six rural towns in China showed that families participating in these programs have a greater understanding of mental illness and less family neglect and abuse (22). Community-based interventions have also been shown to be effective in improving the patients' insight into their treatment and managing their symptoms, which may reduce the number of hospitalizations and reduce the family burden (23).

These pilot data support the feasibility of implementing an LPD rehabilitation program for patients with schizophrenia and the recommendation of the World Health Organization (WHO) that lay nonprofessional health workers deliver community-based psychosocial intervention upgrade services in low-income and developing countries (24). In China, two studies also identified the benefits of LPD for community mental rehabilitation (25, 26). Both studies have their own unique features. One randomized controlled study used mobile text messages for medication reminders, health education, and facilitation of patient care by integrating lay health

supporters, village doctors, and psychiatrists while the lay health supporters for case supervision were patient's families or community volunteers, which showed significant improvement in medication adherence and reduction in relapses and re-hospitalizations (25). The other study recruited peers to join the mental health workforce and assist in providing community rehabilitation services, which increased patients' social communication skills and mood (26). Therefore, diverse lay psychiatric service models can be established in different regions according to their own circumstances. A systematic task-share training course with good supervision methods can help implement the service smoothly.

There are several limitations of this study that should be noted. Although the LPD rehabilitation program was delivered in a fixed format, there is no fidelity test to ensure that the curriculum was delivered exactly as it should be. Additionally, the curriculum of the LPD program has not been validated, and thus, critical areas may not have been included in the curriculum. In the control group, the participants voluntarily attended the drop-in center, but their family members did not receive any assistance from the drop-in center, unlike the experimental group families who received family psychoeducation. Thus, the benefit of LPD may be due to the potential Hawthorne effects, because services offered to the LPD group were more intensive. In future research, this study should be replicated with a larger sample size, validation of the curriculum, and a comparable intervention intensity control group. For the outcome assessments, areas such as employment, community functioning, personal empowerment, and sense of purpose should be included rather than merely focusing on symptom management and social functioning.

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## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethics Committee of West China Hospital of Sichuan University. The patients/participants provided their written informed consent to participate in this study.

## AUTHOR CONTRIBUTIONS

CL and HD conceptualized and designed the work. YC, HD, EY, and KK collected the data. YC and CL analyzed the data and performed the statistics. YC drafted the manuscript, with critical comments from CL and HD. All authors reviewed the manuscript and approved the final version for submission.

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## SUPPLEMENTARY MATERIAL

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# COVID-19-Related Psychosocial Care in General Hospitals: Results of an Online Survey of Psychosomatic, Psychiatric, and Psychological Consultation and Liaison Services in Germany, Austria, and Switzerland

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**Background:** The coronavirus disease 2019 (COVID-19) pandemic was accompanied by new challenges for psychosocial health care to enable the support of affected patients, their families, and staff in general hospitals. In this study, we aimed to describe the structures and procedures put in place by psychosomatic, psychiatric, and psychological consultation and liaison (CL) services in German, Austrian, and Swiss general hospitals, and to elucidate the emerging needs for cooperation, networking, and improvement.

**Methods:** We conducted a cross-sectional online survey between December 2020 and May 2021, using a 25-item questionnaire derived from relevant literature, professional experience, and consultation with the participating professional societies. The survey was disseminated via national professional societies, relevant working and interest groups, and heads of the above-mentioned CL services.

**Results:** We included responses from 98 CL services in the analyses, with a total response rate of 55% of surveyed hospital CL services; 52 responses originated from Germany, 20 from Austria, and 26 from Switzerland. A total of 77 (79%) of the 98 responding CL services reported that "COVID-19-related psychosocial care" (COVID-psyCare) was provided in their hospital. Among these, 47 CL services (61%) indicated that specific cooperation structures for COVID-psyCare had been established within the hospital. A total of 26 CL services (34%) reported providing specific COVID-psyCare for patients, 19 (25%) for relatives, and 46 (60%) for staff, with 61, 12, and 27% of time resources invested for these target groups, respectively. Regarding emerging needs, 37 (48%) CL services expressed



wishes for mutual exchange and support regarding COVID-psyCare, and 39 (51%) suggested future changes or improvements that they considered essential.

**Conclusion:** More than three-quarters of the participating CL services provided COVID-psyCare for patients, their relatives, or staff. The high prevalence of COVID-psyCare services targeting hospital staff emphasizes the liaison function of CL services and indicates the increased psychosocial strain on health care personnel during the COVID-19 pandemic. Future development of COVID-psyCare warrants intensified intra- and interinstitutional exchange and support.

**Trial Registration:** ClinicalTrials.gov NCT04753242, version 11 February 2021.

**Keywords:** COVID-19, psychosocial care, general hospital, consultation and liaison service, psychosomatics, psychiatry, stress, staff support

## INTRODUCTION

The coronavirus disease 2019 (COVID-19) pandemic has been associated with significant psychosocial distress for patients and their relatives (1). Hospitalized COVID-19 patients experienced high rates of delirium, neuropsychiatric disorders, anxiety, depression, acute stress disorder (2) as well as posttraumatic stress disorder (PTSD) (3). Uninfected patients were also affected by the pandemic: Fear, isolation, and disengagement from care worsened premorbid mental disorders (2). Among relatives of patients hospitalized for COVID-19, 23% showed symptoms of psychological distress and 2% showed PTSD 30 days after hospital discharge (3). Prohibition of on-site visits was a special challenge, in particular, in end-of-life situations and case of death. Furthermore, caring for COVID-19 patients was related to the increased psychosocial burden of staff members in the hospital, including risks of becoming infected and of transmission of infection to family members and others, regular donning and doffing of personal protective equipment (PPE), shortage of PPE, exceptional workload, difficult treatment decisions, experience of unusually high numbers of patient deaths, rapidly changing information, reorganization factors, such as the deployment to new COVID-19 wards, and staff shortage (4). To summarize the burdens outlined for the different groups of affected persons, the COVID-19 pandemic is to be considered as a new form of trauma, and an urgent topic for psychosocial medicine (5, 6).

**Abbreviations:** ACLP, Academy of Consultation-Liaison Psychiatry; CL services, Consultation and liaison services; COVID-19, Coronavirus disease 2019; COVID-psyCare, COVID-19 related psychosocial care; DGPM, German Society for Psychosomatic Medicine and Medical Psychotherapy; DKPM, German College of Psychosomatic Medicine; ECLW, European Consultation-Liaison Workgroup; EKNZ, Ethikkommission Nordwest- und Zentralschweiz (Ethics Committee of Northwest and Central Switzerland); EPA, European Psychiatric Association; FTE, Full-time equivalent; HCW, Health care worker; ICU, Intensive care unit; IT, Information technology; ÖGPPM, Austrian Society for Psychosomatics and Psychotherapeutic Medicine; PPE, Personal protection equipment; PTSD, Posttraumatic stress disorder; SAPP, Swiss Academy of Psychosomatic and Psychosocial Medicine; SSCLPP, Swiss Society of Consultation-Liaison Psychiatry and Psychosomatics; SD, Standard deviation; SOP, Standard operating procedure; WPA, World Psychiatric Association; 95% CI, 95% Confidence interval.

In Austria, Germany, and Switzerland, the damage caused by this first wave of the COVID-19 pandemic was managed relatively well, but the emergence of new and more virulent variant strains of the virus led to a devastating second wave of infections at the end of 2020 that resulted in far more hospitalizations and deaths in these countries, running into a subsequent third wave from March to May 2021 (7, 8). In affected regions worldwide, surveys indicated that 50% or more of physicians and nurses experienced clinically relevant levels of anxiety, depression, and acute stress disorder (2). A cross-sectional study about health care workers' (HCW) mental health during the first weeks of the COVID-19 pandemic in Switzerland reported that women (compared to men), nurses (compared to physicians), frontline staff (compared to non-front line workers), and HCWs exposed to COVID-19 patients (compared to non-exposed) reported more psychological symptoms than their peers (9). Comparably, a cross-sectional study in Germany found that the COVID-19 pandemic led to an increase in stress among HCWs (10). This situation raised new challenges for psychosomatic, psychiatric, and psychological consultation and liaison (CL) services in general hospitals worldwide in supporting COVID-19 patients, their relatives, and staff (2).

The definition of psychosomatic, psychiatric, and psychological CL services is structurally blurred and care structures vary between countries. However, these services typically deliver specialized mental health care for patients of general hospitals presenting with both physical and psychosocial health problems. They operate in somatic hospitals in a wide variety of medical settings, mainly on wards, but also in emergency units, and in outpatient clinics, including departments of internal medicine, geriatrics, oncology, surgery, and many more (11). In line with the bio-psycho-social model, they conduct a mix of consultation, liaison, specialized psychological interventions, training, and research. Usually, they have multidisciplinary staffing. Depending on local needs and circumstances, individual CL services vary widely (12); organizationally they are assigned to psychiatric, psychosomatic, or psychological departments. These services are vital in managing the interface between physical and mental health, and in training and supporting somatic hospital staff with regard to psychosocial issues (13). In contrast to many other countries,

in Germany, Psychosomatic Medicine is not a synonym for consultation-liaison psychiatry but represents a comprehensive field as well as a specialized medical discipline (14). Hence, Psychosomatic Medicine in Germany has a larger institutional basis than in many other countries. As a core task, in Germany, Departments of Psychosomatic Medicine at somatic hospitals provide a psychosomatic CL service for the entire hospital, usually in addition to the psychiatric CL service.

During the first wave of the COVID-19 pandemic, the speakers of the working group on consultation and liaison psychosomatics of the German College of Psychosomatic Medicine (DKPM) and the German Society for Psychosomatic Medicine and Medical Psychotherapy (DGPM) entered into an online exchange in order to support each other and to discuss following questions: How do the different CL services deal with the COVID-19 situation at the different hospitals and what can be learned from another? This exchange led to an online survey of psychosomatic, psychiatric, and psychological CL services in somatic hospitals in Germany, Austria, and Switzerland during the second and third waves of the COVID-19 pandemic. The goal was to get to know the situation across CL services and to allow profiting from reported experiences. Our project followed a call for action for mental health research efforts for the COVID-19 pandemic published in *Lancet Psychiatry* in April 2020 (15). It is in line with the recommendations of the Report of the Academy of Consultation-Liaison Psychiatry Task Force on Lessons Learned From the COVID-19 Pandemic, published in July 2021 (2). CL services were challenged to adapt during the pandemic, possibly bringing permanent changes to our profession (16). The overarching objective of our study was to summarize the efforts made in “COVID-19-related psychosocial care” (COVID-psyCare) in general hospitals and to build upon the experience gained so far, to optimize response to the current pandemic and future pandemics. In this context, the aims of this study were:

- (1) to describe the COVID-psyCare structures put in place by psychosomatic, psychiatric, and psychological CL services,
- (2) to review specific services aimed at patients, relatives, and staff, and
- (3) to elucidate emerging needs for cooperation, networking, and improvements.

## MATERIALS AND METHODS

### Study Design and Ethical Approval

This health services research project was carried out as an observational study in the form of a cross-sectional online survey in Germany, Austria, and Switzerland. The study was led by the spokespersons of the working group consultation and liaison psychosomatics of DKPM and DGPM. The survey was performed and sent out together with the respective national societies from Germany (DKPM and DGPM/Chief Physician Conference of Psychosomatic-Psychotherapeutic Hospitals and Departments, CPKA), Austria (Austrian Society for Psychosomatics and Psychotherapeutic Medicine, ÖGPPM), and Switzerland (Swiss Academy of Psychosomatic and

Psychosocial Medicine, SAPPM/ Association of Psychosomatic Chief Physicians, and Swiss Society of Consultation-Liaison Psychiatry and Psychosomatics, SSCLPP). We formed a steering group with representatives from Germany (BS, FV), Austria (CF), and Switzerland (RS, CH). We obtained written statements, declarations, or votes from the responsible ethic committees in Cologne (Ethics Committee of the Medical Faculty of the University of Cologne, 20-1416\_1), Graz (Ethics Committee of the Medical University of Graz; 33-120ex 20/21), and Basel (Ethics Committee of Northwest and Central Switzerland, EKNZ, Req-2020-00861). Participation in the survey was voluntary. We obtained written informed consent from each participant before responding to the survey. Participants could cancel the survey at any time and without giving reasons. The study was registered on ClinicalTrials.gov (NCT04753242, version 11 February 2021).

### Setting and Participants

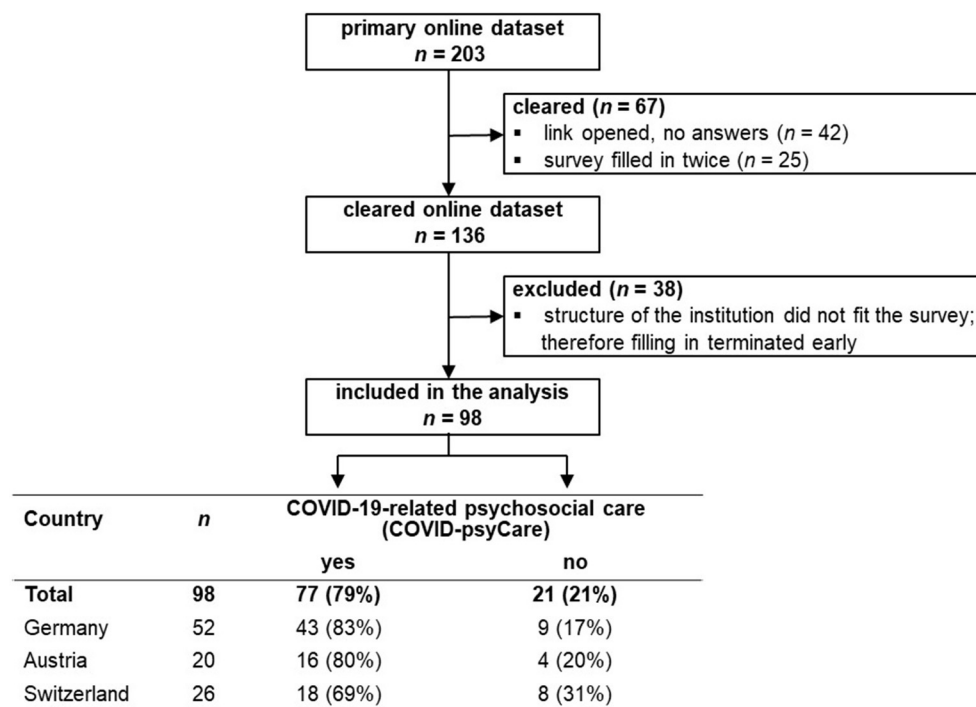
This study was an online survey aiming at psychosomatic, psychiatric, and psychological CL services at general hospitals in Germany, Austria, and Switzerland. We reached out to the representatives of the services *via* the respective national professional societies and relevant working and interest groups (see above).

The number of psychosomatic, psychiatric, and psychological CL services is not known in most countries worldwide; the same is true for Germany, Austria, and Switzerland. Nevertheless, together with the participating professional societies, we tried to get as good an estimate as possible of the number of services to which the survey was sent out. For Germany, the number of CL services in general hospitals with a Psychosomatic Department was estimated at 74 according to the Directory of German Hospitals, the number of CL services in Austria was estimated at 55, and in Switzerland, there was an estimated number of 50 psychosomatic, psychiatric, and psychological CL services. We aimed to contact the heads of these services *via* email to ask for their participation in the survey. Emails were sent out *via* email distribution lists of the national societies, complemented by individual email contacts. One to two reminder emails were sent *via* these lists. We asked the CL services to assign one representative to reply to the survey. The online survey was open from December 2020 to May 2021.

As shown in **Figure 1**, the dataset was cleared from records with the description “link opened, no answers” ( $n = 42$ ), if the link was only opened, but no information was entered into the survey. In case the questionnaire was filled in twice by the same CL service, the most complete record was taken ( $n = 25$ ). Furthermore, records were excluded from the analyses if the structure of the institution did not fit the survey, and therefore filling in usually was terminated during the characterization of the service in the course of the first six questions ( $n = 38$ ).

### Study Questionnaire and Outcome Measures

We used a self-developed questionnaire based on relevant literature (9, 15), expert experience, and consultation with participating professional societies. The survey contained 25



**FIGURE 1 |** Study flow chart.

questions on structural and process variables regarding somatic and psychosocial care structures, services, and procedures that psychosocial CL services have established for patients, their relatives, and staff in general hospitals in the context of the COVID-19 pandemic, as well as needs and requests for the future:

- (1) Characterization of participating hospitals as well as somatic and psychosocial care structures:
  - Characteristics of the hospital: type of hospital, number of beds of the hospital.
  - Characteristics of somatic care: Involvement in the somatic care of COVID-19 patients and the extent the hospitals were maximally occupied regarding the somatic care of COVID-19 patients, both measured with a 6-point Likert scale from 0 = “not at all” to 5 = “very strongly”; structures developed for the somatic care of COVID-19 patients: Wards and units for the treatment of COVID-19 patients as well as special structures for somatic care related to COVID-19 established in the hospitals.
  - Characteristics of psychosocial care: Psychosocial services available in the hospital; professional perspective this survey was answered from; COVID-psyCare established in the hospital; partners involved in cooperation structures for COVID-psyCare; established structures for COVID-psyCare; psychosocial representative in the COVID-19 task force; maximum availability of psychosocial care for COVID-19 patients in terms of time.

- (2) Implementation and use of specific services or procedures of COVID-psyCare for the three target groups patients, their relatives, and hospital staff: Evaluation of the extent to which these services and procedures have proven successful on a 6-point Likert scale from 0 = “not at all” to 5 = “very strongly”; ways of communication with the different target groups about COVID-psyCare services.
- (3) Maximum COVID-19 related burden of the psychosocial teams measured on a 10-point Likert scale from 1 = “not stressed at all” to 10 = “extremely stressed”; needs and requests for the future: Specification of required exchange/support as well as of changes/improvements that are considered essential for the future concerning psychosocial care services in ones hospital in the COVID-19 context.

The representatives of the steering group for Germany, Austria, and Switzerland reviewed the questionnaire and ensured that all specific national aspects were covered. For Switzerland, the study questionnaire was translated by a professional company from German into French and into Italian and proofread by CL employees proficient in French and Italian, respectively. Participants were free to choose the language version to reply to. We provide an English version and the original German version of the questionnaire as **Supplementary Material** to this article.

## Data Management

All collected data were pseudonymized before processing. Data collection was carried out with the online survey tool Questback EFS Fall 2019/license model “Unipark” of

**TABLE 1 |** Sample descriptive.

	<b>Total (n = 98)</b>	<b>Germany (n = 52)</b>	<b>Austria (n = 20)</b>	<b>Switzerland (n = 26)</b>
<b>Estimated overall number of respective CL services</b>	179	74*	55	50
<b>Data available from CL services</b>	55%	70%	36%	52%
<b>Type of hospital; n (%)</b>				
University hospital	29 (30%)	18 (35%)	7 (35%)	4 (15%)
General hospital	44 (45%)	28 (54%)	10 (50%)	6 (23%)
Specialized hospital	15 (15%)	5 (10%)	1 (5%)	9 (35%)
Other type of hospital	10 (10%)	1 (2%)	2 (10%)	7 (27%)
<b>Number of beds of the hospitals</b>				
Number of beds of the hospital; mean (SD; 95% CI)	671 (632; 545–798)	863 (656; 681–1,046)	750 (645; 448–1,052)	227 (262; 120–333)
0–299 beds; n (%)	34 (35%)	7 (14%)	7 (35%)	20 (77%)
300–599 beds; n (%)	24 (25%)	17 (33%)	4 (20%)	3 (12%)
> =600 beds; n (%)	40 (41%)	28 (54%)	9 (45%)	3 (12%)
<b>Psychosocial services available in the hospital (multiple answers possible); n (%)</b>				
Psychosomatic CL service	68 (69%)	48 (92%)	6 (30%)	14 (54%)
Psychiatric CL service	68 (69%)	38 (73%)	15 (75%)	15 (58%)
Psychological CL service	40 (41%)	16 (31%)	16 (80%)	8 (31%)
Other psychosocial services	19 (19%)	9 (17%)	3 (15%)	7 (27%)
<b>Professional perspective this survey was answered from (multiple answers possible); n (%)</b>				
Psychosomatic Medicine	71 (72%)	45 (87%)	10 (50%)	16 (62%)
Psychiatry	25 (26%)	7 (13%)	7 (35%)	11 (42%)
Psychological service/Psychological Department	11 (11%)	1 (2%)	8 (40%)	2 (8%)
Medical psychology	6 (6%)	2 (4%)	4 (20%)	0
Child & adolescent psychiatry & psychosomatics	1 (1%)	0	1 (5%)	0
Other	10 (10%)	3 (6%)	4 (20%)	3 (12%)
<b>Full-time equivalents in consultation-liaison services; mean (SD; min-max)</b>				
Physician positions	1.4 (1.4; 0–5.8)	1.3 (1.3; 0–5.0)	1.5 (1.6; 0–5.8)	1.5 (1.5; 0–4.0)
Psychologist positions	1.7 (2.3; 0–8.85)	1.5 (2.2; 0–8.9)	1.3 (1.9; 0–6.0)	2.9 (3.0; 0–8.0)
Social worker positions	0.2 (0.6; 0–4.0)	0.2 (0.6; 0–4.0)	0.3 (0.5; 0–1.6)	0.2 (0.4; 0–1.0)
Nursing positions	0.2 (0.5; 0–2.5)	0.9 (0.4; 0–2.0)	0.4 (0.7; 0–2.5)	0.2 (0.5; 0–2.0)
Other positions	0.1 (0.4; 0–2.0)	0	0.3 (0.6; 0–2.0)	0.1 (0.4; 0–1.0)

\*CL services in general hospitals with a Psychosomatic Department according to the Directory of German Hospitals.

Questback GmbH via the University of Basel. Questback stores the data collected via the tool in the server park in Frankfurt/Main. This is reliably protected from external access. The BSI-certified data center is subject to high data protection and security requirements according to ISO 27001 based on “IT-Grundschutz.” Subsequently, we stored, processed, and analyzed the data at the University Hospital Basel. Further processing of the anonymized data and interpretation of the results were carried out in cooperation with the German, Austrian, and Swiss members of the above-mentioned steering group.

## Statistical Methods

All analyses were conducted using the statistical software package IBM SPSS Statistics Version 25. Missing data were not imputed. Results were analyzed using descriptive statistics. Numbers and percentages were used to present the data. Here, the prevalence was presented for categorical variables, means, and standard deviations for continuous variables.

## RESULTS

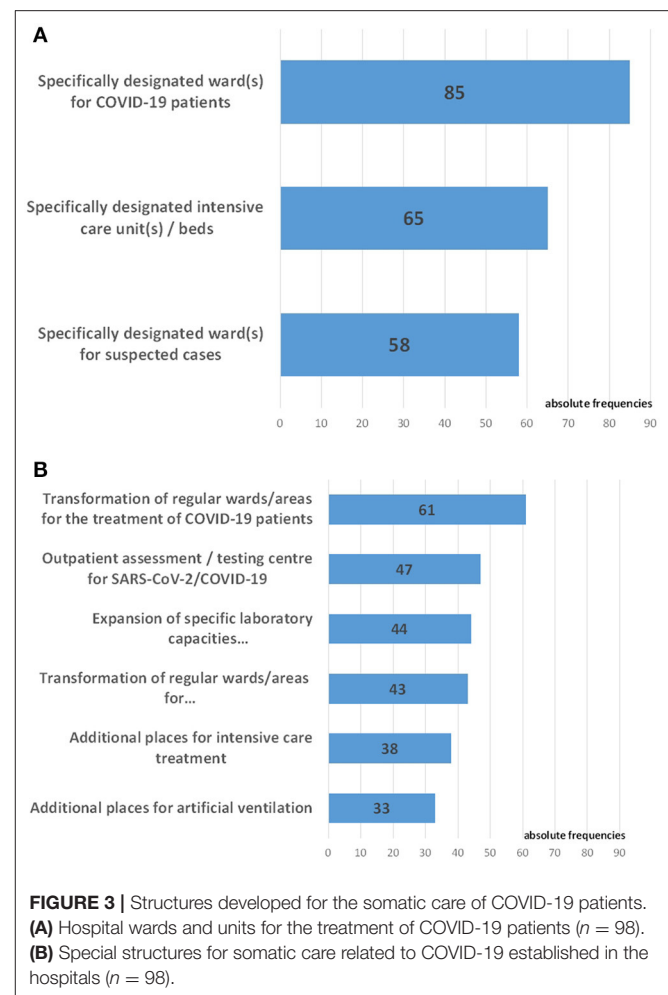
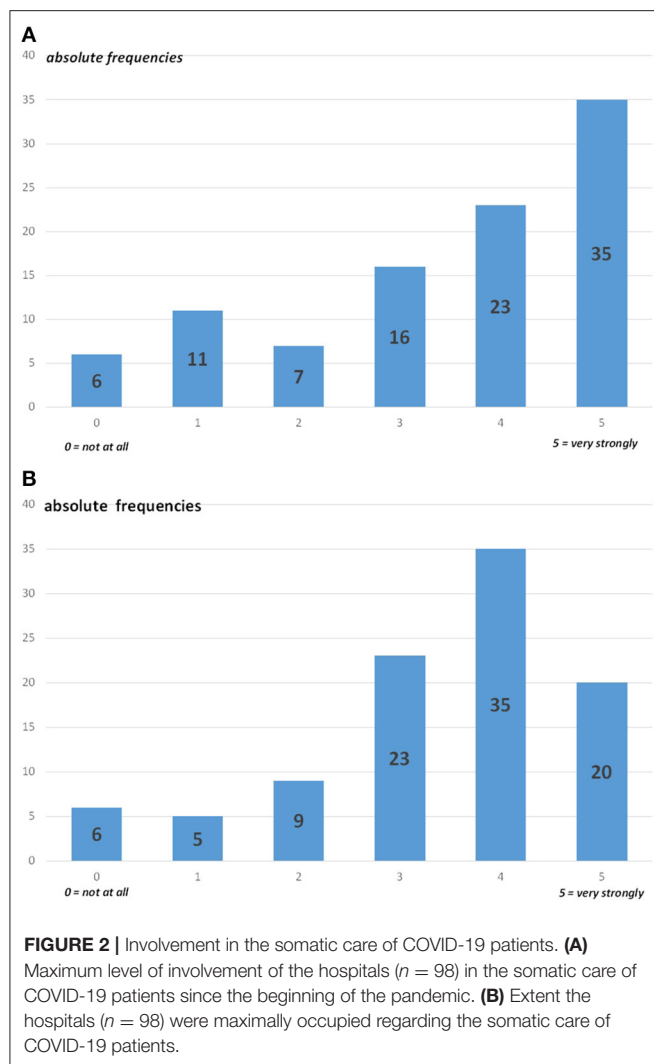
### Study Response

We provide the study flow chart in **Figure 1**. Altogether, we had an initial set of  $n = 203$  responses from Germany, Austria, and Switzerland. A total of 67 responses had to be cleared:  $n = 42$  were records with only missings, indicating that the link was only opened, but none of the questions of the survey was answered;  $n = 25$  were filled in twice by the same CL service; in this case, the most complete record was taken. Furthermore,  $n = 38$  records had to be excluded from the analyses because the structure of the institution did not fit the survey, and therefore filling in usually was terminated during the characterization of the service in the course of the first six questions. This led to a final dataset of  $n = 98$  responses that could be included in the analyses.

### Characterization of Participating Hospitals and CL Services

**Table 1** shows the baseline description of the  $n = 98$  CL services included in the analyses. Thus, data were available





physicians, 1.7 FTE psychologists, 0.2 FTE social workers, 0.2 FTE nursing personnel, and 0.1 FTE other positions (see **Table 1**).

## Somatic Care of COVID-19 Patients: Involvement and Structures

This paragraph shows the somatic care of COVID-19 patients established by the 98 hospitals with participating CL services in this survey. **Figure 2** depicts the maximum level of involvement of the hospital in the somatic care of COVID-19 patients since the beginning of the pandemic (**Figure 2A**) and the extent to which hospitals were maximally occupied regarding the somatic care of COVID-19 patients (**Figure 2B**).

**Figure 3** shows the hospital wards and units where COVID-19 patients were treated as inpatients (**Figure 3A**) as well as newly established special hospital structures for somatic care related to COVID-19 (**Figure 3B**).

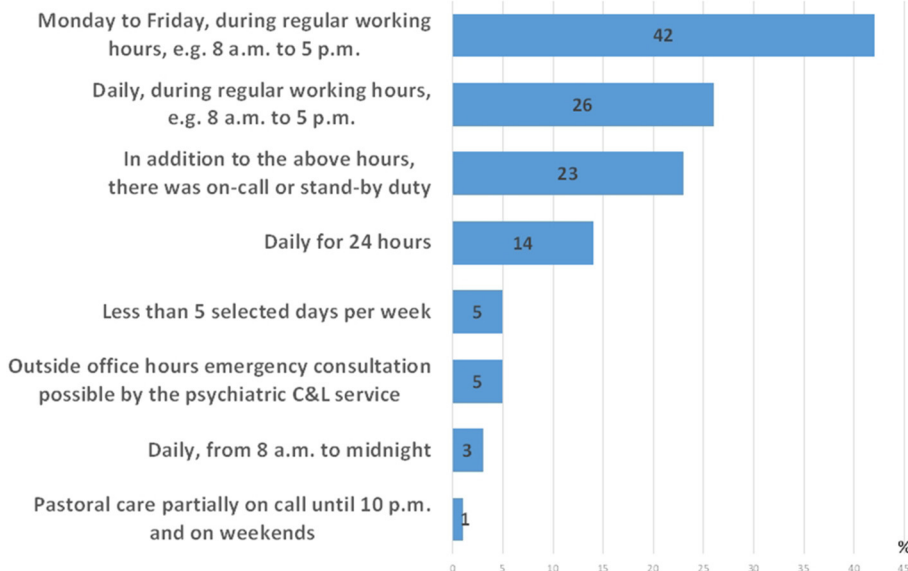
## COVID-psyCare in Somatic Hospitals: Establishment and Structures

A total of 77 of the 98 CL services (79%) reported that in their hospital psychosocial care was provided in connection with

from 55% of CL services based on an estimated denominator of 179 CL services in total as described above. A total of 52 responses originated from Germany (data available from 70% of the CL services), 20 from Austria (data available from 36% of the CL services), and 26 from Switzerland (data available from 52% of the CL services). We provide information on further characteristics of these services, including the type of hospital, psychosocial services available in the hospital, and the professional perspective this survey was answered from in **Table 1**. About psychosocial services available in the hospital, there were 19 entries of “other services” available in addition to the classic ones (e.g., Social service, Psycho-oncology, Pastoral care, Child and adolescent psychiatry, and Psychosomatics). About the professional perspective this survey was answered from, there were 10 entries of “other perspectives” (Psycho-oncology, Pain therapy, Psychotherapy, Internal medicine, Geriatrics, Gynecology) in addition to the classic ones. Typically, CL services were staffed multidisciplinary on average consisting of 1.4 full-time equivalents (FTE)



**FIGURE 4 |** Partners involved in cooperation structures for COVID-psyCare (relative frequencies,  $n = 77$  CL services with COVID-psyCare, multiple answers possible).



**FIGURE 5 |** Maximum availability of psychosocial care for COVID-19 patients in terms of time (multiple answers possible).

COVID-19, whereas 21 CL services (21%) provided no COVID-psyCare. The following information refers to those 77 CL services (43 from Germany, 16 from Austria, 18 from Switzerland) that offered COVID-psyCare.

Among these 77 CL services, 47 (61%) answered that additional cooperation structures had been established within the hospital for psychosocial support in the context of the COVID-19 pandemic, 25 (33%) CL services reported no such additional structures, while 5 (6%) CL services did not answer this

question. The partners involved in these cooperation structures are depicted in **Figure 4**.

Regarding the established structures (multiple answers possible), 44 (57%) of the 77 CL services providing COVID-psyCare stated that existing care structures were refined, 26 (34%) had instituted new care structures, and 17 (22%) reported that their care structure had remained unchanged. Some CL services also commented on which structures for COVID-psyCare had been developed. These were special structures to support staff:

**TABLE 2 |** Specific services or procedures of COVID-psyCare offered by the CL services providing COVID-psyCare ( $n = 77$ ).

Specific services or procedures ...	Number of CL services ( $n^* = 77$ )	Percentage of time utilization mean (min - max; SD)
... for patients	26 (34%)	61% (0 - 100; 27)
... for relatives	19 (25%)	27% (0 - 70; 13)
... for staff	46 (60%)	12% (0 - 100; 25)
Specific services or procedures ...	$n^*$	Extent to which these procedures/offers have proven successful (0 = not at all to 5 = very strongly) mean (min-max; SD)
... for patients		
COVID-19 telephone hotline	16	3.00 (0-5; 1.75)
Consultation staff specifically for COVID-19 referrals	16	3.69 (2-5; 1.01)
Specific protocols/SOPs for common questions	12	3.75 (2-5; 0.87)
Psychosocial COVID-19 Care Team	11	3.18 (0-5; 1.72)
Liaison staff on COVID wards	11	4.00 (1-5; 1.34)
Aftercare services for patients with post-COVID syndrome	9	3.00 (1-5; 1.12)
COVID-19 outpatient clinic	6	1.17 (0-5; 2.04)
Others	4	3.75 (1-5; 1.89)
... for relatives		
COVID-19 telephone hotline also for relatives	13	3.08 (2-5; 1.67)
Specific counseling for relatives	13	3.69 (2-5; 1.82)
Specific protocols/SOPs for supporting relatives	7	3.71 (2-5; 1.11)
Others	3	3.33 (1-5; 2.08)
... for staff		
Telephone hotline for staff	32	2.47 (0-5; 1.50)
Case discussions on patient-related stressful situations	28	3.64 (0-5; 1.42)
Team supervision/facilitated group exchange on how the corona situation is experienced as staff and in the team	25	3.67 (1-5; 1.20)
Workshops to strengthen the resilience of staff (e.g., self-care/resource activation)	12	2.33 (0-5; 1.61)
Creating relaxation opportunities for teams under high stress levels	9	2.67 (0-5; 1.58)
Targeted work with team leaders/supervisors on helpful support measures for staff/teams	8	3.38 (1-5; 1.60)
Training in dealing with psychosocial stress of patients and relatives (recognition, communication, management)	8	2.75 (0-5; 1.98)
Others	6	3.00 (1-5; 1.27)

Absolute frequencies.

**TABLE 3 |** Ways of communication with the different target groups about COVID-psyCare services (absolute frequencies).

	Patients	Relatives	Staff
In person	31	27	30
Word-of-mouth recommendation	15	14	28
Internet	11	13	39
Information via senior executives	–	–	29
Flyer	9	4	15
Notice board	3	0	13
Via the nursing/ward/treatment team	3	3	0
Intranet	3	0	0
Screening	3	0	0
During the patient visit	1	0	–
Via the weekly task force meeting	1	1	0
No special measures	20	25	5

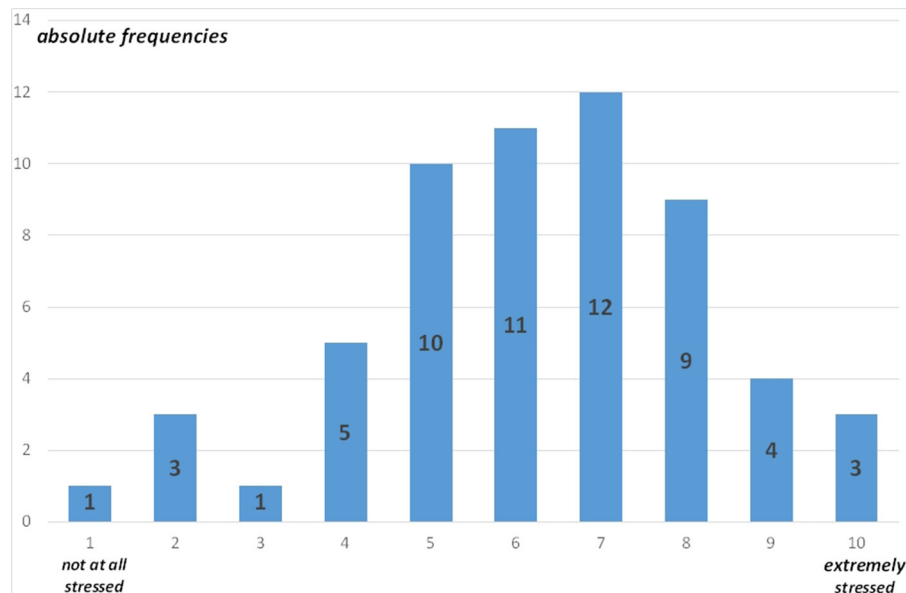
regular team meetings in the COVID intensive care unit (ICU), and as needed, also on other wards as well as telephone hotlines for employees. During home-office due to lockdown, treatment was also conducted *via* telephone. Temporarily overlapping structures were created, which then dissolved again.

Among the 77 CL services providing COVID-psyCare, 32 (42%) reported that in the COVID-19 task force of the hospital a specific representative had been appointed for psychosocial issues, 38 (49%) denied, seven (9%) did not answer that question. Thirteen (17%) CL services reported that a responsible person from the psychosocial departments regularly participated in the task force, 16 (21%) stated that this person selectively participated in the task force on demand. Three (4%) CL services reported the delegation of a responsible person outside the psychosocial departments with regular participation, 2 (3%) with selective participation in the task force meetings. One comment on this question stated that contact was made on demand by the COVID task force.

The maximum availability of psychosocial care for COVID-19 patients in terms of time (multiple answers possible) is depicted in Figure 5.

## Specific Services or Procedures of COVID-psyCare

Table 2 shows the specific services or procedures of COVID-psyCare for the three target groups. Of the 77 CL services that additionally provided COVID-psyCare, 26 (34%) reported the provision of interventions for COVID-19 patients, 19 (25%) reported services for relatives of COVID-19 patients, and 46 (60%) reported additional COVID-19-related services for staff. Regarding the percentage of time utilization of the CL mental health team by COVID-psyCare, 61% of the time was spent on patient care, 12% on relatives, and 27% on staff. The specific



**FIGURE 6 |** Maximum burden of the COVID-19 pandemic on the psychosocial teams (59 entries, absolute frequencies).

services or procedures for the three target groups are depicted in **Table 2**.

Ways of communication with the different target groups regarding the COVID-psyCare services are depicted in **Table 3**.

### Burden of the Psychosocial Teams, Needs, and Requests for Future Development of COVID-psyCare

The maximum burden of the COVID-19 pandemic on the psychosocial teams (mean 6.24, 1–10, SD: 2.04) is depicted in **Figure 6**.

**Figure 7** displays the needs and requests for the future of COVID-psyCare. Among the 77 CL services that reported providing COVID-psyCare, 37 (48%) expressed requests for exchange/support (**Figure 7A**), 39 (51%) suggested changes/improvements that they considered essential for the future (**Figure 7B**).

### Additional COVID-19-Related Aspects With Relevance to CL Services

The following aspects were emphasized as additionally relevant to CL services in the context of the COVID-19 pandemic:

- *Regarding structures and general:* Clear structures and communication; clear allocation of responsibilities as well as spatial and time resources; technical equipment of workplaces with webcam and headset; establishment of intensified collaboration with pastoral care; sensitization to psychosocial emergency care.
- *Regarding staff:* Sufficient personal protection equipment (PPE) for the staff; update and training on COVID-specific hygiene measures and how to use PPE for medical and non-medical personnel early in the pandemic; sensitization to

teams and employees; reducing the anxiety of the staff; clear regulations in cases of suspected COVID-19 infection (before and after the event); staff support also giving relevance to issues that have not been taken into account so far.

- *Regarding patients:* Problems with information technology (IT) for the often geriatric clientele; early involvement in the treatment of COVID-19 patients and their relatives, especially in ICUs.

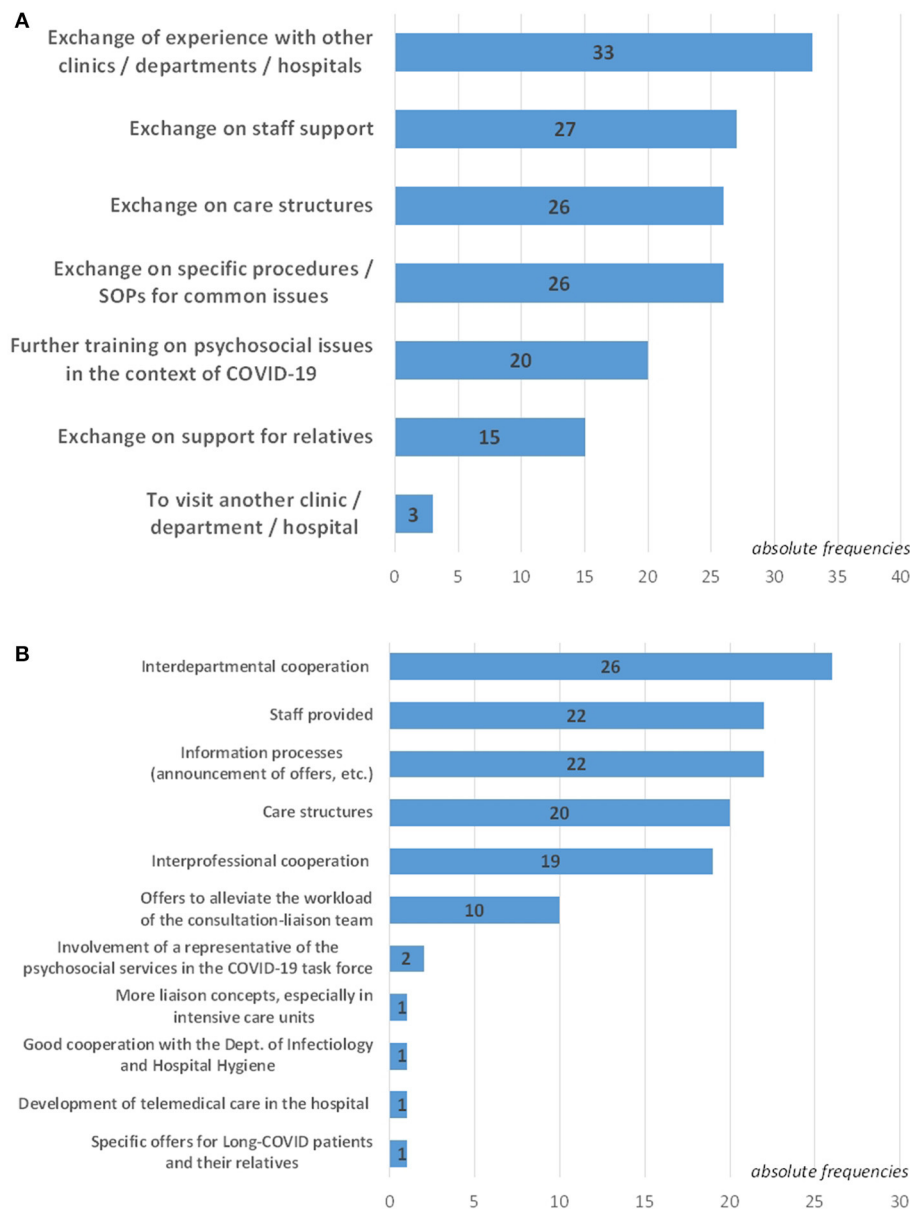
## DISCUSSION

### Key Results

So far, there is little data on psychosocial care by psychosomatic, psychiatric, and psychological CL services in general hospitals during the COVID-19 pandemic. Referring to our three study objectives, our online survey of such services in Germany, Austria, and Switzerland provided the following key results:

- (1) Health care in the COVID-19 pandemic frequently seems to require the development of additional cooperation structures to foster good interdisciplinary and interprofessional cooperation.
- (2) Among 77 CL services reporting COVID-psyCare, 26 (34%) offered specific interventions for patients, 19 (25%) for relatives, and 46 (60%) for staff. Overall, COVID-19 brought the psychosocial burden of the hospital staff more into focus. Nevertheless, regarding the time resources provided for COVID-psyCare, most of the time (61%) was used for the treatment and psychosocial support of COVID-19 patients, following the main focus of CL services on patient care.
- (3) For optimized current and future pandemic response, there is a relevant demand for exchange between CL services





**FIGURE 7 |** Needs and requests for the future. **(A)** Specification of required exchange/support regarding COVID-psyCare ( $n = 37$ ). **(B)** Specification of changes/improvements that are considered essential for the future with regard to psychosocial care services in one's hospital in the COVID-19 context ( $n = 39$ ).

and for improvements of psychosocial care services in general hospitals.

## Characterization of Participating Hospitals and CL Services

In terms of somatic involvement and maximum workload, we were predominantly dealing with hospitals involved in the somatic care of COVID-19 patients. The characteristics of the study respondents were very heterogeneous. The reported psychosocial care structures were diverse and colorful. Historically, hospitals appear to have developed a broad and

heterogeneous landscape of psychosocial care structures. The different characteristics of psychosomatic, psychiatric, and psychological CL services in Germany, Austria, and Switzerland reflect the heterogeneity of psychosocial care in these countries.

## Provision of COVID-psyCare Among Participating CL Services

Up to the third wave of the COVID-19 pandemic, 79% of participating CL services in Germany, Austria, and Switzerland reported an additional provision of COVID-psyCare. Among these CL services, 61% reported that additional cooperation

structures had been established within the hospital for COVID-psyCare. The partners involved in these cooperation structures are in descending order: Psychosomatic Medicine, Pastoral care, Psychiatry, Social services, the Nursing team, Palliative care, Psychology/Medical psychology, Psycho-oncology, Child and adolescent psychiatry, Clinical ethics, Human resources, Workplace health promotion, and Work psychology. These findings indicate that interdisciplinary and interprofessional work has been intensified in dealing with the COVID-19 pandemic. On the other hand, 21% of psychosomatic, psychiatric, and psychological CL services had not developed specific structures or procedures in the context of COVID-19.

## Target Groups of COVID-psyCare for CL Services

For a general comparison of the kind of psychosocial care regularly provided by psychosocial CL services older data from the European Consultation-Liaison Workgroup (ECLW) Collaborative Study are available (17). The final sample of CL services consisted of 56 services from 11 European countries, including 226 consultants seeing 14,717 patients during 1 year in consultation. The study reported a consultation rate of 1% (median; 1.4% mean). The consultant involved the patient's family in 16.3% of the cases. In 44.6% of the cases, the ward staff was also the focus of intervention, however primarily patient-related. In our study, reported interventions were targeted to the bio-psycho-social care of hospitalized COVID-19 patients and their relatives. Additional services and offers were developed to reduce the immense psychosocial burden of staff members in the hospital (18). The most common ways of communication to reach these target groups were in-person contacts, word-of-mouth recommendations, and the internet. In addition, staff members were frequently informed of COVID-psyCare services *via* senior executives.

Many CL services implemented telepsychiatry options for patients as well as for staff (16, 19–21). During the COVID-19 pandemic, it became evident that for many patients, telepsychiatry consultation works well (22), but problems with IT were met for the often geriatric clientele; all in all, a substantial portion of CL work must be performed face-to-face, and it is necessary to triage for appropriateness for telepsychiatry consultation (2).

## Specific Services of COVID-psyCare for Patients

The COVID-19 pandemic has been global health as well as economic shock. Regarding the general population, in a multicentric study ( $n = 20,712$  participants) from Italy, one of the western countries most severely hit by COVID-19, access to mental health services during the pandemic was reported in 7.7% of cases (23); among those referred to mental health services, in 93.9% of the cases ( $n = 1,503$  subjects), a psychological assessment was requested and in 15.7% of the cases ( $n = 252$ ) a psychiatric consultation. In hospitalized COVID-19 patients, COVID-19 comes with a high incidence of psychological distress and neuropsychiatric symptoms; up to

85% of critically ill COVID-19 patients have neuropsychiatric manifestations; also uninfected patients are affected by the pandemic with psychosocial distress and worsening preexisting mental disorders (2, 24, 25). Confronted with this situation, 34% of CL services providing COVID-psyCare reported additional offers for patients. Overall, 61% of the time devoted to COVID-psyCare was directed to patients. Specific services of COVID-psyCare for patients reported in our survey are in descending order: Corona telephone hotline for patients, consultation staff specifically for corona referrals, specific procedures/standard operating procedures (SOPs) for common questions, e.g., for dealing with the anxiety of COVID-19 patients, psychosocial corona-care-team, liaison staff on COVID wards, aftercare services for patients with the post-COVID syndrome, a corona outpatient clinic, switch to telephone consultations - if reasonable and possible, and online services with information and psychosocial support. When asked to what extent these interventions have proven successful, the most favorably assessed and frequently applied interventions for patients were the provision of liaison staff on COVID wards and consultation staff for COVID-19 specific referrals, as well as the provision of specific protocols/SOPs for common questions, e.g., dealing with the anxiety of COVID-19 infected patients.

## Specific Services of COVID-psyCare for Relatives of COVID-19-Infected Patients

Illness-related, psychosocial, and hospital-related factors are risk factors for clinically relevant psychological distress in relatives of COVID-19-infected patients; resilience was negatively associated with anxiety, depression, and PTSD in relatives (1). In dealing with this challenge, 25% of CL services providing COVID-psyCare reported additional offers for relatives. Overall, 12% of the time devoted to COVID-psyCare was directed to relatives. Specific services of COVID-psyCare for relatives reported in our survey are in descending order: Corona telephone hotline for relatives, specific counseling for relatives, specific procedures/SOPs for supporting relatives, an information sheet for relatives, imparting and organization of internet-based video contact opportunities, organization and accompaniment of on-site visits, accompaniment after a death. Frequently offered procedures for relatives rated as most successful were the provision of specific protocols/SOPs for supporting relatives and specific counseling for relatives.

## Specific Services of COVID-psyCare for Hospital Staff

About 60% of CL services providing COVID-psyCare reported additional offers for health care personnel. On average, 27% of the time devoted to COVID-psyCare was directed to hospital staff, as estimated by study respondents. This is as per recent findings on the psychosocial burden of the medical staff, including increased depression/depressive symptoms, anxiety, psychological distress, and poor sleep quality (9, 24, 26–28). Therefore, it is critical that health care organizations have systems in place to support institutional and individual resilience (2). According to our

study, CL services seem to be suitable structures to offer adequate support to staff members in the hospital in times of crises.

Specific services of COVID-psyCare for hospital staff reported in our survey are in descending order: Consultation hours/counseling for staff, a telephone hotline for staff, case discussions on patient-related stressful situations, team supervision/facilitated group exchange on how the corona situation was experienced, workshops to strengthen resilience, creating chill-out opportunities for high-stress teams, work with team leaders on helpful support measures for staff/teams, training in dealing with psychosocial stress of patients and relatives, recommendations for mental hygiene, preparations and discussions on how to deal with triage situations, ethical online consultations, debriefing/ daily review at the ICU, and spiritual support. Among these offers, team supervision and case discussions on patient-related stressful situations were most favorably assessed as having proven successful. In summary, especially interventions related to the liaison function of CL services seem to be perceived as highly useful. Additionally, a similar positive rating was also reported for specific protocols/SOPs that offer guidance for staff members to manage specific challenges in the provision of psychosocial care for COVID-19-infected patients and their relatives.

Ideally, an integrated continuum of care approach should be instituted, including E-Mental Health Interventions (21), crisis leadership consultation and training, staff peer support teams, multidisciplinary rounds, recreation spaces, wellness programs, support groups, and psychological/psychiatric services (29–31). Such coordinated programs may be cost-effective because of their positive effects on absenteeism and turnover (32, 33). A problem may be that hours devoted to staff support usually are non-billable. Of note, although such services have low rates of utilization - lower for medical doctors than for nurses - informal contact with CL staff may enhance interest in service use (2).

Based on the results of a large cross-sectional study from Germany, the COVID-19 pandemic has greatly impacted the following groups, work environments, and living situations: Women, employees with a migrant background, younger employees, individuals with private obligations to care for children and dependents, men concerning dysfunctional coping strategies, people living alone and, when compared to other occupational groups, frontline workers, such as nurses/paramedics and medical technicians (10). To lay the best basis for healthy and efficient work, it seems necessary to take measures especially tailored to the needs of these different groups of HCWs.

## Need for Further Exchange

Our findings point to a relevant demand for further exchange between psychosomatic, psychiatric, and psychological CL services on COVID-psyCare in general hospitals. Issues for this exchange expressed in our survey are in descending order: Exchange of experience with other clinics/departments/hospitals, exchange on staff support, on care structures, on specific procedures/SOPs for common issues, further training on psychosocial issues in the context of COVID-19, and support for

relatives, finally, to visit another clinic/department/hospital, e.g., for an exchange on experience with different SOPs.

## Requests for the Future

Many of the same concerns as for other HCWs can be expected to apply to CL professionals as well - fear of infection, fear of transmitting illness to others, traumatizing experiences during hospital work, moral injury, and burnout (2, 5, 34). In line with this assumption, this study reports a mean value of 6.24 (SD: 2.04) for the maximum burden of the COVID-19 pandemic on the psychosocial teams on a scale of 1 ("not stressed at all") to 10 ("extremely stressed"). Several changes considered essential for the future concerning CL services in the context of COVID-19 were chosen in descending order: improvement of interdepartmental cooperation, the provision of more CL service staff, information processes (announcement of offers, etc.), care structures, interprofessional cooperation, offers to alleviate the workload of the CL team, involvement of a representative of the psychosocial services in the COVID-19 task force, more liaison concepts—especially in ICUs, good cooperation with the Department of Infectiology and Hospital Hygiene, further development of telemedical care in the hospital as well as specific offers for long COVID patients and their relatives.

## Limitations

A strength of our study is that it gives information from a naturalistic health services research project. However, this comes with several limitations: First, comparability between CL services on a national level is limited due to substantial heterogeneity of health care systems and organizational models of psychosomatic, psychiatric, and psychological CL services in Germany, Austria, and Switzerland. Second, a selection bias needs to be considered when interpreting the results of this study: As the study has been initiated by spokespersons of psychosomatic CL services, a lower threshold to participate in this study may have existed for psychosomatic as compared to psychiatric and psychological CL services despite structured efforts to reach as many psychiatric, psychosomatic, and psychological CL services as possible. Especially in Germany and Austria, where the professional societies for Psychiatry did not participate in the mailing of the study, psychiatric CL services were underrepresented. Furthermore, it is possible that mainly CL services that have established COVID-psyCare participated in this survey leading to an overestimation of its provision. Third, when interpreting the fact that ~79% of participating CL services have reported the provision of specific COVID-psyCare whereas approximately 21% did not provide such care, it needs to be considered that the reported level of involvement of the hospitals in the somatic care of COVID-19 patients also differs significantly. A total of 74 general hospitals/CL services (76%) reported medium to very strong involvement and 24 general hospitals/CL services (24%) reported no or low involvement in the somatic care of COVID-19 patients. Fourth, it became apparent that precise national denominators of CL services were not available and that it was very difficult to get a good estimate for the total number of CL services in the participating countries. Fifth, the response rate of our study was limited to 55% of the surveyed CL services. Overall,

the CL services that responded to our survey may not fully represent the entire field; thus, the generalizability of our results is restricted. Sixth, we used an *ad hoc* developed questionnaire for the survey, which may further affect the generalizability of our findings. However, to the best of our knowledge, there are practically no referenceable instruments, as the COVID-19 pandemic represents an unprecedented public health emergency. Seventh, each response was finished by one representative of the respective CL service which presumably brought subjective bias to the response. Eighth, data quality was affected by missing answers. Finally, our survey period from 12/2020 to 05/2021 met a similar, yet, a somewhat different, second and third wave of COVID-19 infections in Germany, Austria, and Switzerland which may have influenced the study results (for a comparison of figures of waves of COVID-19 infection numbers and death rates during the survey period see, for example, <https://coronavirus.jhu.edu/map.html>) (8); however, the broad professionalization in dealing with this new challenge took place mainly at the beginning of the pandemic in spring 2020 of which we believe to be able to give an informative insight. Therefore, the main measures may have been taken before the time of the survey. Likewise, services might also have been further adapted after the end of this survey in May 2021.

## Clinical and Organizational Implications - Lessons Learned From This Survey

In the following, we summarize the lessons learned from this survey, concerning the clinical and organizational implications of our study. Thereby, our findings are put into perspective by referring to the viewpoints of international scientific associations such as the Academy of Consultation-Liaison Psychiatry (ACLP) (2), the European Psychiatric Association (EPA) (35), and the World Psychiatric Association (WPA) (36). Given the likely lagged effects of the COVID-19 pandemic on health and the economy, the total demand for mental health services is likely to stay at increased levels, potentially for several years (35). According to the main focus of CL services on patient care, most of the time resources provided for COVID-psyCare are needed for the treatment and psychosocial support of COVID-19 patients with and without mental disorders (36). Additionally, staff support is gaining in importance: Health and social care workers and other frontline professionals who have experienced high levels of psychological distress during the crisis require sustained support. Efforts to protect their general and mental health need to be scaled up (2, 35): To be better prepared for future challenges like pandemics or catastrophes measures supporting the maintenance of the health status of staff members should be implemented comprehensively, especially as preventive procedures (2). The staff should be involved in this process to create tailored measures; a combination of top-down and bottom-up approaches might be most successful. In the sense of precision medicine, CL offers should be more specifically tailored to vulnerable groups concerning gender, age, family and living situation, migrant background, frontline workers, etc. (10). A greater focus will be put on resilience. This survey underlines the importance of liaison concepts:

Summarizing, particularly those interventions for patients, their relatives, and for hospital staff, that are typically associated with the liaison function of CL services seem to be perceived as highly beneficial, not only in times of crisis. This suggests a high level of implementation and integration of most participating CL services in their hospitals (11). However, still, liaison models often are not implemented because of restricted financial resources or a lack of awareness concerning the importance of liaison services. Hospital management and health policy could contribute to better care of patients and better support of HCWs by implementing liaison concepts. Within the health care system, the development of additional cooperation structures seems necessary to foster good interdisciplinary and interprofessional cooperation with the aim of more integrated mental health care that is better linked to primary and community services. Our findings also confirm that the pandemic has increased the provision of telemedicine services (2, 35). The task will be to reshape mental health service delivery in a way that traditional mental health service models can reasonably be blended with digital services. Of course, long-term mental health support plans need to be tailored to individual country contexts (35).

## Research Implications

Our study attracted great international interest indicating a great need for international exchange on psychosocial health care in the context of the COVID-19 pandemic. According to this need, our study has been expanded into an international survey in 11 other European countries, Iran, and parts of Canada (ClinicalTrials.gov NCT04753242). We will report on this large international survey and its results elsewhere. Considering that the survey questions involve issues of patients, their relatives, and staff in general hospitals, future studies should make efforts to collect data from them to obtain more comprehensive results. Further studies should analyze the prevalence of COVID-19 infection, morbidity, mortality, and mental health of CL professionals during the pandemic (2).

## CONCLUSION

In summary, the COVID-19 pandemic seems to have put things under a burning glass and has highlighted problems in our health care systems. The results of our survey underline the crucial role of psychosomatic, psychiatric, and psychological CL services in an integrative and comprehensive health care approach to the challenges of the COVID-19 pandemic in general hospitals. They illustrate reported adjustments of CL service structures to meet the most urgent challenges of this pandemic in the somatic hospital setting by the provision of COVID-psyCare for patients, their relatives, and hospital personnel.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.



## ETHICS STATEMENT

Ethical clearance for this study was acquired from the Ethics Committee of Northwest and Central Switzerland in Basel/ Switzerland, the Ethics Committee of the Medical Faculty of the University of Cologne/ Germany, and the Ethics Committee of the Medical University of Graz/ Austria. Each participant provided informed consent that his/her responses could be used for analyses that would be reported in scientific publications.

## AUTHOR CONTRIBUTIONS

RS, BS, CF, CH, FV, and GM contributed to the conception and design of the study. RS organized the translation of the survey and wrote the first draft of the manuscript. GM, RS, and FV ensured clarifications on data protection. RS, BS, CF, and FV took care of the necessary ethical votes. RS and CH arranged study registration. GM and NR programmed the online survey. RS, BS, CF, CH, FV, SS, and UH contributed to the dissemination of the survey. BS and FV were study contact persons for Germany, CF for Austria, CH and RS for Switzerland. NR, GM, and BS organized the database. BS performed the statistical analysis. CF and FV wrote sections of the manuscript. All authors contributed to the development of the survey questionnaire, interpretation of the data, manuscript revision, and read and approved the final manuscript.

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## SUPPLEMENTARY MATERIAL

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**Data sheet 1** | English version of the online survey.

**Data sheet 2** | German version of the online survey.

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# Specialized Biopsychosocial Care in Inpatient Somatic Medicine Units—A Pilot Study

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**Introduction:** Specialized biopsychosocial care concepts are necessary to overcome the dualism between physical and psychosocial treatment in acute care hospitals. For patients with complex and chronic comorbid physical and mental health problems, neither standardized psychiatric/psychosomatic nor somatic care units alone are appropriate to their needs. The “Nuremberg Integrated Psychosomatic Acute Unit” (NIPA) has been developed to integrate treatment of both, psychosocial and physical impairments, in an acute somatic care setting.

**Method:** NIPA has been established in inpatient internal medical wards for respiratory medicine, oncology and gastroenterology. One to two patients per ward are regularly enrolled in the NIPA treatment while remaining in the same inpatient bed after completion of the somatic care. In a naturalistic study design, we evaluated treatment effects by assessment of symptom load at admission and at discharge using the Patient Health Questionnaire (PHQ) and the Generalized Anxiety Disorder Scale-7 (GAD-7). Furthermore, we assessed the severity of morbidity using diagnosis data during treatment. At discharge, we measured satisfaction with treatment through the Patient Satisfaction Questionnaire (ZUF-8).

**Results:** Data from 41 NIPA patients were analyzed (18–87 years, 76% female). Seventy-eight percent suffered from at least moderate depression and 49% from anxiety disorders. Other diagnoses were somatoform pain disorder, somatoform autonomic dysfunction, eating disorder and posttraumatic stress disorder. Hypertension, chronic lung diseases and musculoskeletal disorders as well as chronic oncological and cardiac diseases were the most common somatic comorbidities. Treatment resulted in a significant reduction of depressive mood (admission:  $M = 10.9$ ,  $SD = 6.1$ , discharge:  $M = 7.6$ ,  $SD = 5.3$ ,  $d = 0.58$ ,  $p = 0.001$ ), anxiety (admission:  $M = 10.6$ ,  $SD = 4.9$ , discharge:  $M = 7.3$ ,  $SD = 4.1$ ,  $d = 0.65$ ,  $p < 0.001$ ) and stress (admission:  $M = 6.0$ ,  $SD = 3.6$ , discharge:  $M = 4.1$ ,  $SD = 2.5$ ,  $d = 0.70$ ,  $p < 0.001$ ). Somatic symptom burden was reduced by NIPA treatment (admission:  $M = 10.9$ ,  $SD = 5.8$ , discharge:  $M = 9.6$ ,

$SD = 5.5$ ,  $d = 0.30$ ), albeit not statistically significant ( $p = 0.073$ ) ZUF-8 revealed that 89% reported large or full satisfaction and 11% partial dissatisfaction with treatment.

**Discussion:** NIPA acute care is bridging the gap for patients in need of psychosocial treatment with complex somatic comorbidity. Further long-term evaluation will show whether psychosocial NIPA care is able to reduce the course of physical illness and hospital costs by preventing hospitalization and short-term inpatient re-admissions.

**Keywords:** integrated care, biopsychosocial approach, psychosomatics, internal medicine, chronic disease, Psychiatric Medicine Units, psychotherapy

## INTRODUCTION

Worldwide, there are proven and established treatment structures regarding somatic issues on one hand and psychosomatic-psychiatric care on the other. However, a high prevalence of mental comorbidities is present in patients with chronic and complex somatic diseases affecting daily clinical practice. Studies show regularly an elevated somatic comorbidity in people with psychiatric and psychosomatic diagnoses and higher rates of manifest mental illnesses in patients with physical disorders (1, 2).

A meta-analysis estimated the prevalence of clinically relevant depression in patients suffering from chronic obstructive pulmonary disease (COPD) to be 40% and the prevalence of anxiety and panic disorders to be 37% (3, 4). The prevalence of depressive disorders is estimated to be about 20% in patients with heart failure and coronary artery disease, which is 2 to 4 times higher than in the general population (5–7). Additionally, other diagnoses e.g. posttraumatic stress or bodily distress disorder are regularly seen in chronic physical diseases (8, 9). Other psychosomatic syndromes can also significantly increase the symptom severity and suffering in somatic diseases. Patients with, e.g. eating disorders, show a high prevalence of typical gastrointestinal symptoms such as constipation or diarrhea up to ileus-like symptoms which are difficult to treat without knowledge of the underlying psychosocial problems (10).

These observations lead to a constant adaptation of the health system to define and characterize psychosomatic complexity, which is represented by an update of the international classification of diseases. With new diagnostic entities (DSM V: Somatic Symptom Disorder, ICD 11: Bodily Distress Disorder), the high degree of overlap and mutual interaction of psychological and physical symptoms, especially in chronic conditions such as cardiovascular, lung or cancer diseases, is taken into account (11–14). Attention to these clinical phenomena is highly needed, considering elevated mortality rates, functional impairment and societal costs due to lost workdays and greater utilization of health care associated with psychiatric and psychosomatic comorbidity in somatic patients (15–17). In addition, prolonged hospitalization for mental disorders has been demonstrated for some constellations (18).

In everyday clinical practice, these implications can be observed frequently and in a wide variety of manifestations, e.g. intense anxiety reduces self-management skills in dealing with the somatic disease. This can be illustrated by COPD patients

fearing physical exertion and therefore tend to be less willing to exercise or withdraw from active daily life due to fears of social stigmatization (19).

Depressive symptoms such as anhedonia or lack of interest, social withdrawal and sleep disturbances are associated with a significantly reduced quality of life of patients and result in an impaired ability to actively cope with the disease. Panic attacks occurring in the context of anxiety disorders with somatic comorbidity often lead to repetitive emergency room admission and inpatient treatment, increasing the risk of worsening the underlying chronic disease. Recent research has shown that depressive symptoms are associated with a higher risk of COPD exacerbation and poorer prognosis and therefore highlights the need for psychotherapeutic (co-) treatment (19–21). Strong associations between psychological distress and treatment results, disease progression, and quality of life have also been shown for coronary artery disease (7, 22). Both depressive and anxiety disorders are associated with an increased risk of cardiovascular morbidity and mortality [e.g. (23)]. Accordingly, the related statement of the German Society of Cardiology explicitly recommends psychotherapeutic interventions to address these associations (24). Furthermore, there are patients with somatization on internal wards, who show twice as many utilizations and medical care costs than non-somatizing patients (25).

Psychiatric and psychosomatic comorbidities are usually not diagnosed in the common somatic setting, so that these disorders often become chronic (15, 26–28) and result in repetitive and mismatched inpatient admission and treatment with increasing overall financial costs for the health system (29, 30). These patients have rather the problem of refused admission to medical wards (when mental comorbidity is striking) and to psychosomatic or psychiatric wards (when somatic symptoms are too severe) and sometimes even suffer from premature discharge because of difficulties in treatment within the framework of traditional care structures (31). When psychosomatic or psychiatric comorbidities interfere with care, treatment staff can quickly become overwhelmed, which in turn leads to shortages of care for this patient population (32).

According to Huyse and Stiefel, complex medically ill patients benefit from “complexity models, such as the biopsychosocial model—which focuses more on interactions such as compliance, the quality of the patient–doctor relationship, or interdependence between psychological stressors and physical disorders, rather than on separate disease identities [to] enrich



the quality of service delivery to these patient groups" [(33), p. 257].

## Biopsychosocial Inpatient Treatment Models

Following a short overview of the existing integrated care models and their development, the NIPA concept is presented as an innovative psychosomatic treatment unit and sorted into the previous models in terms of its ability to close the gap in biopsychosocial care for the chronically and complex medically ill. Initial clinical data evaluating treatment effect complete the report.

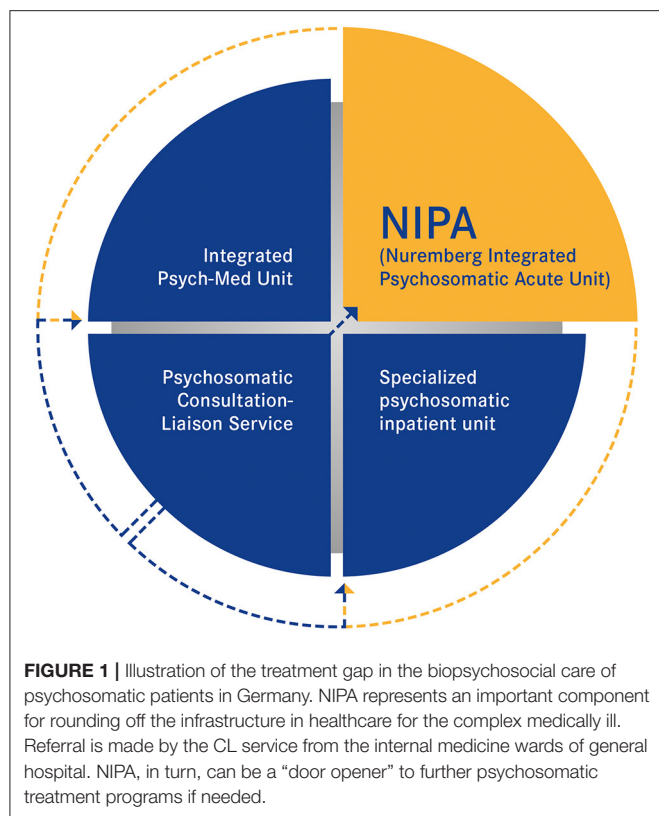
There have been efforts around the world in recent decades to enhance integrated care models, which are defined as coordinated care between general and mental health as well as social service disciplines. There is a wide range of models that differ in terms of the manner of collaboration between these care providers (34). Inpatient integrated treatment is particularly necessary when outpatient care is insufficient due to the severity, complexity or acute nature of the complaints and when multimodal treatment is needed (1). The first milestone in this integrated perspective was the development and expansion of consultation and liaison services (C-L) of psychiatry in general hospitals, which was started in the 1950s/60s in the USA and established in the following decades in Europe, Asia and Oceania as well as in South America (35). There are also forms of integration that provide for physical health liaison within mental health settings (36). Kathol et al. present a four-level categorization of integrated treatment models, which are termed Medical Psychiatry Units or Psychiatric Medicine Units, and are referenced by treatment programs worldwide (37). Type I and Type II follow the traditional approach and are most likely to be represented by psychiatric wards with somatic C-L support (Type I) or general hospital wards with psychiatric C-L support (Type II) (38, 39). Type III and IV would care for patients with moderate to severe psychiatric and somatic symptom severity in a stronger organizational integration whereas Type IV units "can diagnose and treat the same medical problems as general-medicine wards, regardless of the severity, together with any psychiatric condition generally handled in an acute-care psychiatric ward" [(31), p. 355]. Since the type definitions overlap and are sometimes not distinctive enough (40), the summarizing term Complexity Intervention Unit, which was introduced by Kathol et al. in 2009 (41) seems more appropriate for all these units providing more integrated biopsychosocial care. All over the world these kinds of clinical organizations were developed, differing in administration (psychiatry or general medicine), location (e.g., public, academic or private hospital) and specification (e.g., specific chronic conditions or disorders) (42). The vast majority of these units are more or less large bed units that allow for multimodal treatment of mental as well as somatic comorbidities (e.g., by lockable rooms on the one hand and oxygen supplies on the other). Illustrative examples can be found, among many others, in Alberque et al. (31) (USA), Wullschleger et al. (43) (Switzerland), Buckley et al. (44) (Ireland), Leue et al. (45) (Netherlands), Gertler et al. (46) (Australia) or Nomura et al. (47)

(Japan). The most numerous efforts in this regard are directed toward the integrated care of severe mental illnesses especially schizophrenia, bipolar disorder and major depressive disorder (2, 48).

In Germany, a particular development of integrated medicine influenced by psychodynamic theory resulted in the establishment of the independent medical specialty of psychosomatic medicine with its distinct care units (35, 49). Modern psychosomatic therapy has since integrated a variety of method- and disorder-specific techniques drawn from a number of approved therapeutic disciplines (50). Comparable developments of independent psychosomatic specialties can be found in a number of countries, such as the other German-speaking states of Switzerland and Austria, but also, for example, in Japan and the Baltic states (51–54). The population treated in psychosomatic care is slightly different to Medical Psychiatry Units e.g., in the United States. The most prevalent diseases which are treated in psychosomatic wards in Germany are affective and anxiety disorders as well as somatoform disorders, eating disorders and trauma- and stress-related disorders in a specialized group setting with a comprehensive treatment plan (35, 50). Meta-analyses showed moderate to strong treatment effects of inpatient psychosomatic treatment in terms of symptom severity, well-being, and overall functioning (55, 56). However, complex and chronic somatically ill patients often do not fit to these standard psychosomatic wards due to the severity of their physical comorbidities and their need of continuous and specialized somatic co-care.

In line with the presented developments in integrated care, models have been established to realize an inpatient biopsychosocial based approach which exceeds the general treatment options of typical specialized psychosomatic inpatient units (**Figure 1**, bottom right). These units do not provide adequate internal medicine care competence and equipment appropriate to complex medically ill patients. In Nuremberg General Hospital, like in many others around Germany, a psychosomatic C-L service is integrated throughout the hospital and enables comprehensive psychosomatic co-care of complex and chronically diseased patients by specialized staff assigned to the departments (35, 57) (**Figure 1**, bottom left). For patients with higher biopsychosocial treatment needs, this therapy model is not always sufficient. Building on this, a specialized inpatient Psychiatric Medicine Unit for biopsychosocial care of the comorbid somatic and mentally ill patients has been successfully established (57) (**Figure 1**, top left). In this unit, patients are treated who require regular somatic co-care but who are resilient enough to fit effectively into a psychotherapeutic treatment program lasting 6 to 8 weeks consisting of group-based interventions.

Finally, there remains a gap in the care of chronically ill and often complex patients who need psychotherapeutic treatment, because they are often too impaired to participate in this kind of intensive treatment plan, especially in a group setting. For these patients, all kinds of established psychosomatic inpatient, but also outpatient care is often inaccessible, in particular due to limited mobility. Furthermore, these patients often have no idea how to benefit from biopsychosocial support because of



lack of psychotherapeutic experience, which often results in reduced motivation for therapy. Additionally, the experience of psychotherapists in working with physically ill patients is generally low.

Another major challenge in accessing these patients are the long waiting times for psychosomatic treatment, often lasting several weeks to months. For complexly ill, mentally and somatically impaired patients, however, longer waiting times often mean a prolongation of hospitalization in somatic wards, which worsens the course of the disease, as explained above. A more rapid treatment perspective is therefore urgently needed. The Nuremberg Integrated Psychosomatic Acute Unit (NIPA) is trying to improve treatment options regarding all these points and therefore, closes the gap in biopsychosocial care in Germany (Figure 1, top right).

As for evaluation, we would like to explore whether NIPA treatment is resulting in a reduction of symptom burden and is well accepted by the patient group. Thus we hypothesize that anxiety and depressiveness and stress can be significantly reduced and satisfaction with the treatment is high.

## MATERIALS AND METHODS

### Clinical Setting

Since 2018, NIPA has been established in inpatient wards of the departments for respiratory medicine, oncology and gastroenterology. One to two patients per ward are regularly included in the NIPA treatment while remaining in the same

inpatient bed after somatic stabilization. This approach enables the acute admission of patients to psychosocial mental health care and increases the patient's compliance and motivation since the treatment setting continues to include specialized somatic treatment. For example, hospitalized COPD patients with frequent recurrent inpatient treatments (19) benefit more from this approach.

The initiative for psychosocial co-treatment is taken by the internal medicinal referral to a psychosomatic consultation—liaison service for assessment, partially in the course of a proactive consultation model to improve case detection (41). In case of relevant psychosomatic comorbidity, a psychosomatic-psychotherapeutic treatment in NIPA is planned. After improvement of somatic complaints, psychosomatic conditions are the leading cause for hospitalization and patients are included in NIPA treatment.

An individual treatment plan is drawn up in line with therapy goals, which are achieved by low-threshold, psychoeducational and practice-based interventions. The aim of this biopsychosocial approach is 1. to provide acute and low-threshold psychosocial support and 2. to serve as a “door-opener” for further specialized psychosocial mental health treatment in the outpatient or day-care sector. This is realized by extending the patients' disease model by focusing on psychosomatic and psychosocial understanding of disease processes, supporting stabilization and resource activation. The important psychoeducational content is based especially on clarifying psychosomatic relationships between anxiety, tension and stress with bodily signals such as dyspnea and pain, as well as showing the effectiveness of relaxation on the organism, combined with experiential exercises (e.g., relaxation and imagination techniques). In NIPA, resource activation is primarily focused on those areas of life that are important to the patients and addresses how participation can still be achieved despite limitations—perhaps with the help of additional resources or with a slightly different intensity than before. Another important component is the optimization of drug therapy, e.g. with regard to improving sleep or energy. Physical therapy units aim at enhancing mobilization and movement. The NIPA treatment modules are designed to motivate chronically ill patients without overwhelming them. The multi-professional psychosocial team consists of medical, psychological, art therapeutic, body therapeutic, physiotherapeutic and nursing professional staff. Another important treatment module is the co-management by social services, that focuses on improvement of domestic care as well as on helping with the integration to diverse community offers (e.g., outpatient social psychiatry services) (Table 1).

The psychosomatic therapy program is continuously accompanied by daily medical and nursing care of the somatic ward. By virtue of close, interdisciplinary exchange, a quick response to any changes in the general somatic condition can be guaranteed through specialized somatic care.

### Psychometric Instruments

In a naturalistic study design, we assessed the severity of morbidity using diagnosis data during treatment. The severity

**TABLE 1 |** NIPA treatment modules.

Intervention	Details
Psychosomatic medical round	
Psychotherapy	e.g., Psychoeducation, development of psychosomatic disease model, motivation, psychosocial interventions
Psychosomatic nursing	e.g., Therapeutic diary, collecting positive experiences, training of adaptive sleeping or nutrition routines
Physical therapy	e.g., Mobilization, respiratory therapy
Relaxation techniques	e.g., PMR, imagination
Art- or body therapy	Therapy with perception and expression of feelings, thoughts and actions through movement and body experience or creative work through visual art media.
Social service	e.g., Support in applying for assistance regarding domestic care, integration to diverse outpatient community offers

of mental health problems at admission and at discharge was measured using the Patient Health Questionnaire [PHQ (58, 59)] and Generalized Anxiety Disorder Scale-7 [GAD-7 (60)]. Furthermore, a general assessment of treatment, the relevance to patient needs and satisfaction with treatment were evaluated using the Patient Satisfaction Questionnaire [ZUF-8 (61)].

## Statistical Analyses

A Wilcoxon signed-rank test was calculated to compare the severity of symptoms at admission and discharge. Data are presented in mean (*M*) and standard deviation (*SD*) with  $p < 0.05$  considered statistically significant. Statistical power (*d*) was additionally calculated. In a second step, we calculated the effective symptom changes of the individual patients by a description of frequencies in the sample. Both PHQ (PHQ9/PHQ15) as well as GAD-7 enabled this by categorization of symptom severity (severe, moderate, mild, normal symptom manifestation). We described patients with improvement over two categories as having major improvement, and patients with improvement over one category as having moderate improvement. Satisfaction of treatment (ZUF-8) was analyzed by a description of frequencies in the sample.

## RESULTS

Until May 2021 we treated 41 patients in NIPA for an average of 15.7 days ( $SD = 5.3$ , min = 2, max = 29). The mean age of the patients was 59.9 years (18–87 years). Thirty-one patients were female (76%) and 10 male (24%). The sample showed a high rate of various mental and somatic diagnoses (Table 2). Besides the main psychosomatic diagnosis, the median of mental comorbidities was 1 (min = 0; max = 4), the median of somatic comorbidities was 9 (min = 2, max = 25). We included 38 patients in the analysis of the treatment outcome (admission vs. discharge) due to missing data regarding the symptom evaluation at discharge from three patients (two because of premature dropout from treatment, one because of necessary transfer to intensive care unit due to somatic symptom worsening).

Treatment ( $n = 38$ ) resulted in a significant reduction of depressive mood (admission:  $M = 10.9$ ,  $SD = 6.1$ , discharge:  $M = 7.6$ ,  $SD = 5.3$ ,  $d = 0.58$ ,  $p = 0.001$ , PHQ9), anxiety (admission:  $M = 10.6$ ,  $SD = 4.9$ , discharge:  $M = 7.3$ ,  $SD = 4.1$ ,  $d = 0.65$ ,  $p < 0.001$ , GAD-7) and stress (admission:  $M = 6.0$ ,  $SD = 3.6$ ,

discharge:  $M = 4.1$ ,  $SD = 2.5$ ,  $d = 0.70$ ,  $p < 0.001$ , PHQ). Changes in somatic symptom burden were not significant (admission:  $M = 10.9$ ,  $SD = 5.8$ , discharge:  $M = 9.6$ ,  $SD = 5.5$ ,  $d = 0.30$ ,  $p = 0.073$ , PHQ15) (Figure 2).

In terms of categorical symptom changes regarding the whole sample, in depressive symptoms (PHQ9) seven patients (18.4%) showed major and 11 (28.9%) showed moderate improvement whereas three patients (7.9%) showed minor worsening and one patient (2.6%) showed major worsening. Sixteen patients (42.1%) reported no categorical changes in depressive symptoms. Eight patients (21.1%) showed major and 14 patients (36.8%) showed moderate improvement in anxiety symptom burden (GAD-7), whereas two patients (5.3%) reported minor worsening, one patient (2.6%) reported major worsening and 13 patients (34.2%) were unchanged. In somatic symptoms (PHQ15) we found moderate improvement in 16 patients (42%), minor worsening in six patients (15.8%), major worsening in two patients (5.3%) and no categorical change in 14 patients (36.8%). In total, four patients (10.5%) reported no improvement in any of the outcome measures. Out of these, two showed a symptom increase on all scales.

Eighty-nine percent of patients reported large or full satisfaction with treatment (ZUF-8) (somewhat or very helpful in dealing with their problems; therapy meeting most or almost all of their needs, respectively). No patient rated the therapy unsatisfactory, although 11% of patients reported partial dissatisfaction across all diagnosis groups. Key items regarding this dissatisfaction were 1. because they expected greater extent of support regarding their somatic issues and 2. wished for more assistance in dealing with their resulting problems appropriately (Figure 3).

## DISCUSSION

Our clinical experience with the NIPA concept to date shows advantages for both patients and treatment providers. Firstly, it offers biopsychosocial stressed, underserved patient groups the chance of specialized and individualized psychosomatic-psychotherapeutic treatment. Secondly, it expands the intervention repertoire of psychosomatic clinics in the urgently needed expansion of treatment capacities for somatically ill patients. In terms of categorization according to Kathol et al. (37), the NIPA concept can be classified a type III Psychiatric

**TABLE 2 |** Diagnoses in NIPA treatment.

<b>n = 41</b>	<b>n</b>	<b>%</b>
<b>Mental disorders</b>		
Depression		
<i>Depressive episodes, recurrent depressive disorder (mild–severe)</i>	32	78,0
Anxiety		
<i>Phobias, Panic Disorder</i>	20	48,8
Somatoform disorders		
<i>Somatization Disorder, Somatoform autonomic dysfunction, Persistent somatoform pain disorder</i>	14	34,1
Eating disorders		
<i>Anorexia nervosa</i>	2	4,9
<b>Somatic comorbidities</b>		
Limitations in mobility/dependence on medical devices	23	56,1
Hypertension	23	56,1
Chronic lung disease		
<i>COPD, Emphysema, Asthma, Chronic respiratory failure, Bronchiectasis, etc.</i>	20	48,8
Gastrointestinal diseases		
<i>Chronic or acute gastritis, Diverticulitis, Constipation, Nausea, etc.</i>	20	48,8
Musculoskeletal disorders		
<i>Osteoporosis, Fibromyalgia, Dorsalgia, etc.</i>	16	39,0
Urogenital diseases		
<i>Hyperplasia of prostate, Retention of urine, Anuria, Vesicointestinal fistula etc.</i>	10	24,4
<i>Cachexia</i>	10	24,4
Oncological diseases		
<i>Malignant neoplasm, secondary neoplasm</i>	9	22,0
Cardiac diseases		
<i>Heart failure, Ischemic heart diseases, Persistent atrial fibrillation, etc.</i>	9	22,0
Thyroid diseases		
<i>Hypothyroidism, thyroid nodule</i>	9	22,0
Diabetes	8	19,5
Vascular diseases		
<i>Atherosclerosis</i>	4	9,8
Nephrological diseases		
<i>Chronic kidney disease, unspecified kidney failure, acute renal failure</i>	3	7,3

Medicine Unit, as it is a highly specialized integrated treatment context, but does not treat medical patients with high acuity. Thus, it can be well-described by the more modern term Complexity Intervention Unit, which is characterized, in particular, by administration through an alliance of general and psychosomatic care, location in general hospital with physical and mental health safety features and capabilities to treat patients with high health complexity (41). Most of these Complexity Intervention Units worldwide focus on integrated treatment of severe mental illnesses e.g., to provide acute medical care for people with serious psychotic symptoms. NIPA, by comparison, follows rather the psychosomatic treatment approach, which has its unique developmental roots in Germany and focusses of

biopsychosocial support for a wide range of patients, including affective and anxiety disorders, trauma-related syndromes as well as bodily distress in complex medically ill patients. Similarly to patients with severe mental illnesses, this broader group of patients could gain a substantial enhancement of physical health outcomes due to biopsychosocial care e.g. in terms of education and motivation to more adequate health behavior or improvement of their activity level (62).

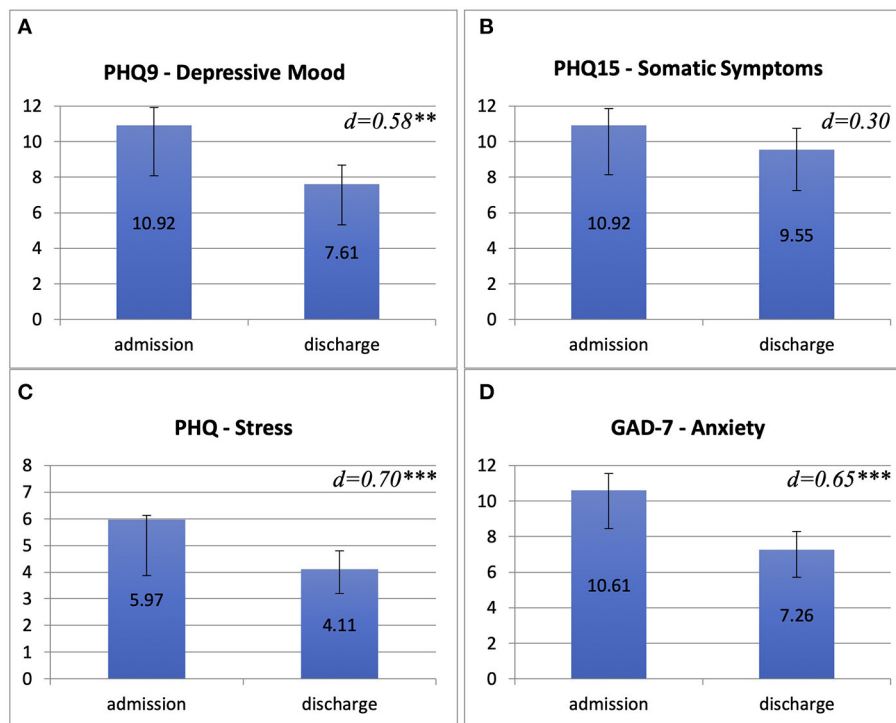
The treatment structure comes closest to the model of integrated medical/psychiatric care at the Royal Prince Alfred Hospital in Sydney presented by Gertler et al. especially with regard to the small size of the unit (4–5 beds) and indication defined by: “(1) the patient’s medical/surgical problem no longer required acute care on the general ward and residual symptoms or continuing physical care would not interfere with the patient’s participation in the ward therapeutic program; (2) the patient was sufficiently mobile to attend to his/her personal hygiene; (3) the patient was transferred to the [Medical Psychiatry Unit] on a voluntary basis; (4) the patient was not suffering from drug or alcohol withdrawal, but could have a history of such abuse; [...] (6) internists and surgeons who had previously cared for the patient on the general wards would continue to supervise the relevant aspects of the patient’s management and be available in an emergency either to consult, or if necessary, accept transfer back to their care.” [(46), p. 27].

Differences exist in the NIPA-team’s stronger multidisciplinary approach to specialized professions such as psychologists, art therapists, and social workers in combination with specialized nursing staff. Furthermore, the unique approach of a decentralized structure enables flexibility. Integrated beds across multiple somatic wards ensure specialized biopsychosocial therapy within the somatic clinical setting best suited to patients’ physical symptoms. As requested by Caarls et al., this further lowers the barriers to mental treatment and allows for even greater integration and faster availability of care (39). Increased awareness of mental health comorbidities among the internal medical staff is stimulated by proactive case detection, which is ensured by the psychosomatic C-L structures (35). The multimodal treatment of this complex medically ill patient group also brings benefits to the medical and nursing staff in general hospital since their need of support is well-described in the literature [e.g. (32)].

In Germany, there were already models that provided for the psychosomatic care of “interspersed beds” [“Steglitzer Belegbetten-Modell” (63)] or implemented the psychosomatic treatment unit [“Marburg Model” (64)] on somatic wards. The outlined potentials were observed, but also difficulties in maintaining these structures due to a lack of specialized psychosomatic indication options since these models were the stand-alone treatment possibilities back then. The realization of the NIPA concept is only achievable if it is established in addition to a wide range of treatment options offered by highly qualified psychosomatic care, thus closing the gap that has existed to date in the treatment of complexly and chronically ill patients.

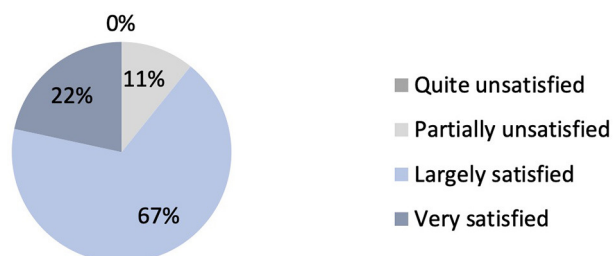
Nevertheless, the need for precise definition of admission criteria for integrated units is frequently stated in the literature (39, 48). The occasionally vague nature of these criteria is a





**FIGURE 2 |** NIPA treatment outcomes compared between admission and discharge on the four symptom scales assessed. We compared means (Y-axis) of Patient Health Questionnaire for depressive mood [PHQ9, (A)], Patient Health Questionnaire for somatic symptoms [PHQ15, (B)], PHQ-stress-scale (C) and Generalized Anxiety Disorder Scale-7 [GAD-7, (D)].

### ZUF-8 - Satisfaction with treatment



**FIGURE 3 |** Reported satisfaction with NIPA treatment as measured by Patient Satisfaction Questionnaire (ZUF-8). Diagram shows the frequency of the different levels of satisfaction.

risk for confounding communication and connectivity between patients, caregivers, referrers, and payers that we could also observe in the NIPA treatment context. To improve this situation, Caarls et al. formulated five clusters of criteria for the decision making regarding admission to integrated care units, involving patient and organizational variables as well as psychiatric and medical symptoms and treatment capabilities, which can be assessed by a short questionnaire (39). Another

promising, systematic approach, the INTERMED method, identifies complex patients and filters out their treatment priorities quickly and economically using a structured interview (65). An improvement of the NIPA concept in this regard is useful and intended. The major economic challenges faced by many Medical Psychiatry Unit approaches (35) are alleviated in the NIPA treatment by, among other things, lower additional costs as the model leverages existing infrastructure.

The results of the treatment show that it was effective in reducing symptoms of depression, anxiety and stress in patients with complex and chronic somatic comorbidity, which support the assumption that NIPA can close a gap in the care of these complex medically ill patients. A considerable proportion of the treatment group showed measurable categorial improvements in symptom burden. The minor changes in somatic symptoms correspond in part to the clinical impression, since the treated group is composed of multiple and often chronically ill patients with often severe somatic comorbidities, thus a significant improvement would not be expected. Furthermore, PHQ 15 measures the distress caused by the occurrence of a wide range of somatic symptoms over a reference period of four weeks. Considering that NIPA treatment has a median duration of about two weeks, the PHQ-15 does not seem to be an appropriate measure to gain meaningful data in terms of assessing change. For this purpose, future evaluations of treatment should involve measurements of health-related quality of life within a shorter reference time period. Due to

the naturalistic design, this evaluation study has limitations, especially with regard to the currently still small sample size and a missing control group.

Regarding a more comprehensive evaluation of treatment success, long-term follow-up data are needed to be collected and supplemented by data regarding the quality of life and the frequency of further medical treatment plus a comparison with an appropriate control cohort, which could be obtained, for example, by propensity score matching in the framework of a quasi-experimental design, as presented by Baumgardt et al. (66). Existing evidence indicates the possibility of reducing healthcare utilization and associated socioeconomical costs due to sufficient treatment, e.g. in patients with somatoform disorders (67). Corresponding observations would be of great assistance to many integrated biopsychosocial treatment units such as NIPA. A transfer of this therapy program into other medical disciplines (e.g., surgery) seems to be reasonable. Clinical impressions indicate that the treatment could be helpful for patients of all genders. The greater number of female patients reported for psychosomatic treatments in general was also evident in NIPA treatment. However, due to the small sample, no valid statements can be made on gender aspects.

Naylor et al. state: “From an integrated care perspective, some of the most significant opportunities for innovation lie in building community-facing liaison services that stretch beyond hospital boundaries and work in new ways with community partners” [(36), p. 54]. Especially with regard to many patients’ huge dependence on social care or support from the social sector, the strengthening and improvement of collaboration between inpatient and outpatient facilities as well as between the different mental, physical and social caregivers is necessary (48). The NIPA concept, with its focus on low-threshold interventions and the “door-opener” function for further treatment options, e.g., more intensive biopsychosocial treatment in specialized psychosomatic inpatient units or outpatient psychotherapeutic

and social psychiatric care, takes important steps in this direction, although these need to be further intensified and extended.

The here presented treatment model requires careful and interdisciplinary coordination, especially with regard to a rapid response to somatic deterioration in the frequent case of multimorbidity. If this challenge is met with effective procedures, one of the great strengths of the concept will have been realized, because this kind of individualized treatment would not be possible in any other context.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. The patients/participants provided their written informed consent to participate in this study.

## AUTHOR CONTRIBUTIONS

PK, EK-K, BS, and CW contributed to the conception and design of NIPA. JE, AD, and MW supported the concept and contributed to the realization in their departments. PK performed the statistical analyses and wrote the first draft of the manuscript. CW wrote sections of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

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# Palliative Psychiatry for Patients With Severe and Persistent Mental Illness: A Survey on the Attitudes of Psychiatrists in India Compared to Psychiatrists in Switzerland

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**Objectives:** Palliative psychiatry is a new approach for the care of patients with severe and persistent mental illness (SPMI) which systematically considers biological, psychological, social, and existential factors of care. To assess the attitudes of psychiatrists in India toward palliative psychiatry for patients with SPMI and to compare these to the attitudes of psychiatrists in Switzerland.

**Methods:** In an online survey, data from 206 psychiatrists in India were collected and compared with data from a previous survey among 457 psychiatrists in Switzerland.

**Results:** Psychiatrists in India generally considered it very important to prevent suicide in SPMI patients (97.6%). At the same time, they considered it very important to reduce suffering (98.1%) and to ensure functionality in everyday life (95.6%). They agreed that palliative psychiatry is important for providing optimal care to SPMI patients without life-limiting illness (79.6%) and considered palliative psychiatry as indicated for patients with SPMI (78.2%). By contrast, curing the illness was considered very important by only 39.8 % of respondents. Relative to psychiatrists in Switzerland, psychiatrists in India were significantly more concerned about preventing suicide and less willing to accept a reduction in life expectancy, even at the expense of quality of life in patients with severe and persistent schizophrenia and recurrent major depressive disorder. At the same time, they were significantly more likely to advocate palliative psychiatry.

**Conclusion:** Most of the participating psychiatrists in India agreed that palliative psychiatry can be indicated for patients with SPMI. The comparison with psychiatrists in Switzerland highlights the need to take account of cultural differences in future studies of this kind. In summary, this study shows the potential of palliative psychiatry as a genuine biopsychosocio-existential approach which systematically integrates biological, psychological, social, and existential factors of care.

**Keywords:** severe and persistent mental illness, ethics, psychiatry, palliative care, futility, cultures

## INTRODUCTION

The emerging field of palliative psychiatry (or palliative care approaches in psychiatry) is increasingly attracting interest (1–9). Palliative psychiatry is based on accepting that some psychiatric symptoms are irremediable and offer a valuable means of improving the quality of life of patients with severe persistent mental illness (SPMI) [(8–11) for an in-depth discussion of the concept of SPMI]. While curative psychiatry focusses on the mental disorder with the aim of (partial) remission of symptoms, palliative psychiatry aims at improving quality of life by means other than symptom remission. Analogous to palliative care in somatic medicine, palliative psychiatry systematically considers biological, psychological, social, and existential factors of care (8). For example, a palliative care plan for a person suffering from treatment-refractory schizophrenia may include stopping clozapine (if the patient is distressed by frequent blood draws and major weight gain and experiences only low improvement of psychotic symptoms), prescribing diazepam for panic attacks due to therapy-refractory delusions, scheduling group physiotherapy (if the patient experiences a reduction of subjective stress levels after exercise and wishes to expand his social circle), providing housing where unusual behavior is tolerated (as long as it does not endanger others), scheduling regular home visits by a mental health nurse to alleviate feelings of loneliness, and offering advance care planning to ensure future care (including end-of-life care) is aligned with the wishes, values, and beliefs of the patient. Thereby, palliative psychiatry is a genuine biopsychosocio-existential approach [see (12, 13)] that includes but is not limited to end-of-life care for persons with SPMI. For detailed case examples of palliative psychiatry, please see (7, 14, 15).

When should psychiatrists apply palliative psychiatry? At what point should psychiatrists focus on palliative psychiatry in addition to curative psychiatry or on its own? In countries with relatively scarce health care resources, additional ethical difficulties may arise, and multiple factors must be considered when deciding whether to forego further treatment, including duration and severity of illness, response to previous treatment and whether it is appropriate to focus on palliative psychiatry before all other possible options have been exhausted (e.g., due to a lack of financial resources) (16). In low- and middle-income countries, where only a small fraction of mentally ill patients receive adequate psychiatric treatment (17–19), the appropriateness of palliative psychiatry is an open question.

Since the 1980s, India's Kerala region has shown how requisite palliative care can be provided free of charge, using local resources (20–25). In their descriptive study, Philip et al. (25) reported that in recent years in Kerala, patients with SPMI were commonly included in these programs. However, having a SPMI was also an important factor in early program drop out, and here as elsewhere, patients with mental illness receive insufficient health care.

However, it would be counterproductive and ethically questionable to misuse palliative psychiatry as a low-cost option for cost- and time-intensive psychiatric service users. As McGorry et al. (6) noted, an under-resourced mental health

system may consign patients to persisting and unremitting illness, and we concur that no group of patients should be neglected in this way. Rather, palliative psychiatry is about abandoning harmful or ineffective treatment to focus on quality of life and reduction of suffering when further curative treatment is considered futile (6, 10, 25).

Attitudes of healthcare professionals toward palliative psychiatry for patients with SPMI might be influenced by cultural aspects and economic factors of the respective healthcare system. Therefore, in this study, the question is addressed how palliative psychiatry is understood and lived in psychiatric practice in different cultures. This survey of psychiatrists in India and its comparison with a previously published survey from Switzerland (9, 26, 27) sought to assess attitudes among psychiatrists on palliative psychiatry, especially for patients with SPMI. The comparison is especially interesting because, as discussed above, differing resource levels as well as cultural differences may promote different views of palliative psychiatry and treatment of psychiatric patients with SPMI.

## METHODS

The online survey investigated attitudes among psychiatrists in India to palliative psychiatry, physician-assisted dying, and compulsory interventions for patients with SPMI. The data were then compared with findings from an earlier survey of Swiss psychiatrists using the same questionnaire (9, 26, 27). The methods used in India are described below.

### Sampling and Data Collection in India

Between April and June 2020, 3,056 members of the Indian Psychiatric Society were sent an email containing information in standard text and a survey link, followed at intervals by four reminders. In total, 562 of the recipients clicked on the link; 285 commenced the process, and 206 of these completed the questionnaire using the SoSci Survey tool. Recipients were informed that, by clicking on the supplied link, they were giving their informed consent. For reasons of data security, no record was kept of whether the questionnaire had already been processed (i.e., no IP address was saved). Only fully completed questionnaires were included in the data analysis.

### Survey and Case Vignettes

The survey and case vignettes from the corresponding previous studies were translated from the original German version to English and adapted for the use in India (9, 26–28). The adaptation and translation was done by MT, taking into account specifics of the Indian context such as the illegality of Medical Assistance in Dying. In particular, the questions on palliative sedation and physician assisted dying were removed as well as all questions and a case vignette concerning anorexia nervosa. Like the original questionnaire, the adapted version comprised 23 items, along with three additional questions on age, gender, and year of graduation from medical school (as proxy marker for career duration). Five items related to the general treatment of patients with SPMI, and eight related more specifically to palliative psychiatry and SPMI.

**TABLE 1 |** Case vignettes.**Patient 1:**

- 33-year-old male
- Schizophrenia with onset at age 17; no significant comorbidities
- Positive symptoms: auditory and visual hallucinations, persecutory delusions
- Negative symptoms: apathy, social withdrawal, poverty of speech (all rated severe)

Despite long-lasting high-dose pharmacological treatment (several atypical neuroleptics, haloperidol, clozapine, and their combinations), as well as electroconvulsive therapy, the patient has never been free from positive or negative symptoms. Multiple psychotherapies employing various approaches have also failed to stabilize the patient or to improve his quality of life. He does not wish to continue treatment because he feels it is too intrusive. While the positive symptoms predominated in the years immediately following his initial diagnosis, he developed severe negative symptoms, as well as aggression and self-injurious behavior, including burning himself with cigarettes. The negative symptoms and his strong functional deficits are exacerbated by chronic unemployment and an inability to live independently. Additionally, the patient has no family system, and his persisting illness has left him completely isolated, with no social contacts and no hobbies or interests. Two experts have declared that he possesses decision-making capacity regarding his illness and its treatment.

**Patient 2:**

- 40-year-old male
- Recurrent major depressive disorder; no significant comorbidities
- Somatic symptoms: energy loss, insomnia, and fatigue
- Persistent suicidal ideation over the past 20 years; current acute and concrete suicidal intent

The patient underwent different forms of intensive, long-term, evidence-based psychotherapy, including specialized approaches such as cognitive behavioral analysis system of psychotherapy (CBASP) and interpersonal psychotherapy (IPT). Both psychotherapy alone and in combination with adequate treatment trials of antidepressants [selective serotonin reuptake inhibitors, tricyclic antidepressants, venlafaxine, augmentation with lithium and antipsychotic medications (quetiapine and aripiprazole)] failed to improve his depression, and the patient experienced significant adverse effects from several of the medications. Exhausted, he has decided to undergo electroconvulsive therapy as a last resort. However, maintenance electroconvulsive therapy again proved insufficient to prevent the reappearance of suicidal ideation; indeed, his symptoms worsened. Experiencing severe hopelessness, the patient states that his quality of life is very poor, that he doesn't want to deal with his illness anymore, and that he plans to commit suicide in the near future. Two experts have declared that he possesses decision-making capacity regarding his illness and its treatment.

Case vignettes modified from Brenner et al. (28) and Baweja et al. (30) and adapted in the style of Trachsel et al. (9), Hodel et al. (26), and Stoll et al. (27).

Before answering the respective questions, to standardize the understanding of palliative care, participants were presented with the WHO definition of palliative care as “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual” (29). This generic definition of palliative care was used because a consensus definition of palliative psychiatry is not yet available. Additionally, each of the two case vignettes was accompanied by five items (see **Table 1** for the case vignettes and **Supplementary Material** for the complete list of items). In each instance, participants responded on a 7-point Likert scale ranging from 1 (*not important/strongly disagree*) to 7 (*very important/strongly agree*), with a midpoint at 4 (*moderately important/neutral*).

## Ethics Approval

An ethics application was submitted to and approved by the Government Medical College, Thiruvananthapuram (HEC.No.01/06/2020/MCT, dated 07.02.2020).

## Statistical Analysis

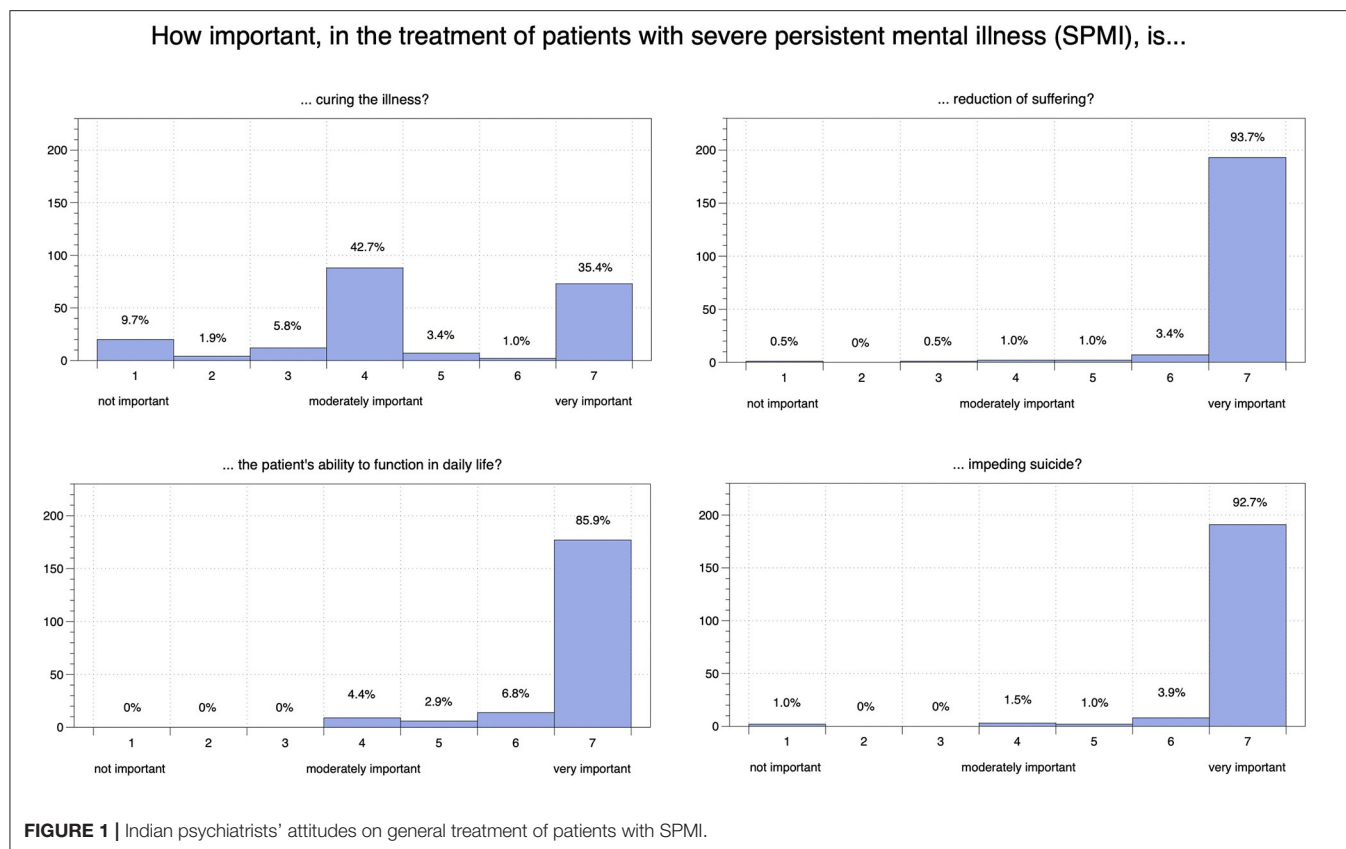
Arithmetic means were calculated for the age and work experience items. Percentages were calculated for gender data, and for items related to treatment of patients with SPMI, palliative psychiatry in SPMI,

and the two case vignettes. For better readability and to facilitate interpretation, 7-point Likert scale data were combined into three categories: *disagree/unimportant* (1–3), *neutral* (4), and *agree/important* (5–7).

To compare the samples from India and Switzerland, data from the respective samples were first tested for normal distribution. As the Shapiro-Wilks test indicated that all items deviated significantly from the normal distribution ( $p < 0.05$ ), these differences were evaluated using the non-parametric Mann-Whitney  $U$  test, equivalent to Wilcoxon's rank-sum test. Mean and median values were calculated for each item, as the median is more useful for interpreting non-normally distributed data (31). In addition, the effect size  $r$  was determined to further refine interpretation of the data (31, 32). For increased readability, we report only significant comparisons with at least medium effect size ( $r \geq 0.3$ ) in the text. IBM SPSS Statistics Version 25 was used to perform the statistical analysis.

## RESULTS

The fully completed questionnaires ( $n = 206$ ) represented a response rate of 6.7%. Of these, 33% were women and 67% were men, with a mean age of 43.1 years ( $SD = 12.9$ , range = 25–78 years) and mean career duration of 19.0 years since graduation ( $SD = 12.9$ , range = 2–56 years).



## General Views on Treatment of Patients With SPMI

Most participants (42.7%) felt it was moderately important to *cure* patients with SPMI; 39.8% regarded this as (very) important while 17.5% considered it less important to cure the illness (see **Figure 1**). Overwhelming majorities considered it (very) important to *reduce suffering* in patients with SPMI (98.1%), to help them *function in daily life* (95.6%), and to *impede suicide* (97.6%).

## General Views on Palliative Care and Its Applicability to Different Forms of SPMI

48.1% of respondents disagreed that the term *palliative* relates directly to end of life while 25.7% agreed and 26.2% were neutral. Regarding the proposition that *palliative care is indicated for some patients with SPMI*, 78.2% agreed while 16.5% remained neutral and only 5.3% disagreed. Regarding the proposition that *palliative care models are an important means of providing optimal care for patients with non-terminal illnesses*, 79.6% agreed while 13.1% remained neutral and 7.3% disagreed. Regarding the proposition that SPMI can be a terminal illness, 35.0% disagreed while 34.5% remained neutral and 30.6% agreed; a further 26.7% strongly disagreed, and 19.9% strongly agreed.

Most participants (81.6%) agreed that in severe, chronic, and therapy-refractory schizophrenia a palliative approach would be suitable with just 4.9% disagreeing (see **Figure 2**). The view that

a palliative approach would be appropriate in cases of severe, chronic, and therapy-refractory bipolar disorder was shared by 68.9%, by 66.0% in cases of severe, chronic, and therapy-refractory depression, and by 54.4% in cases of severe, chronic, and therapy-refractory substance disorder with 11.7, 13.1, and 19.9% disagreeing, respectively.

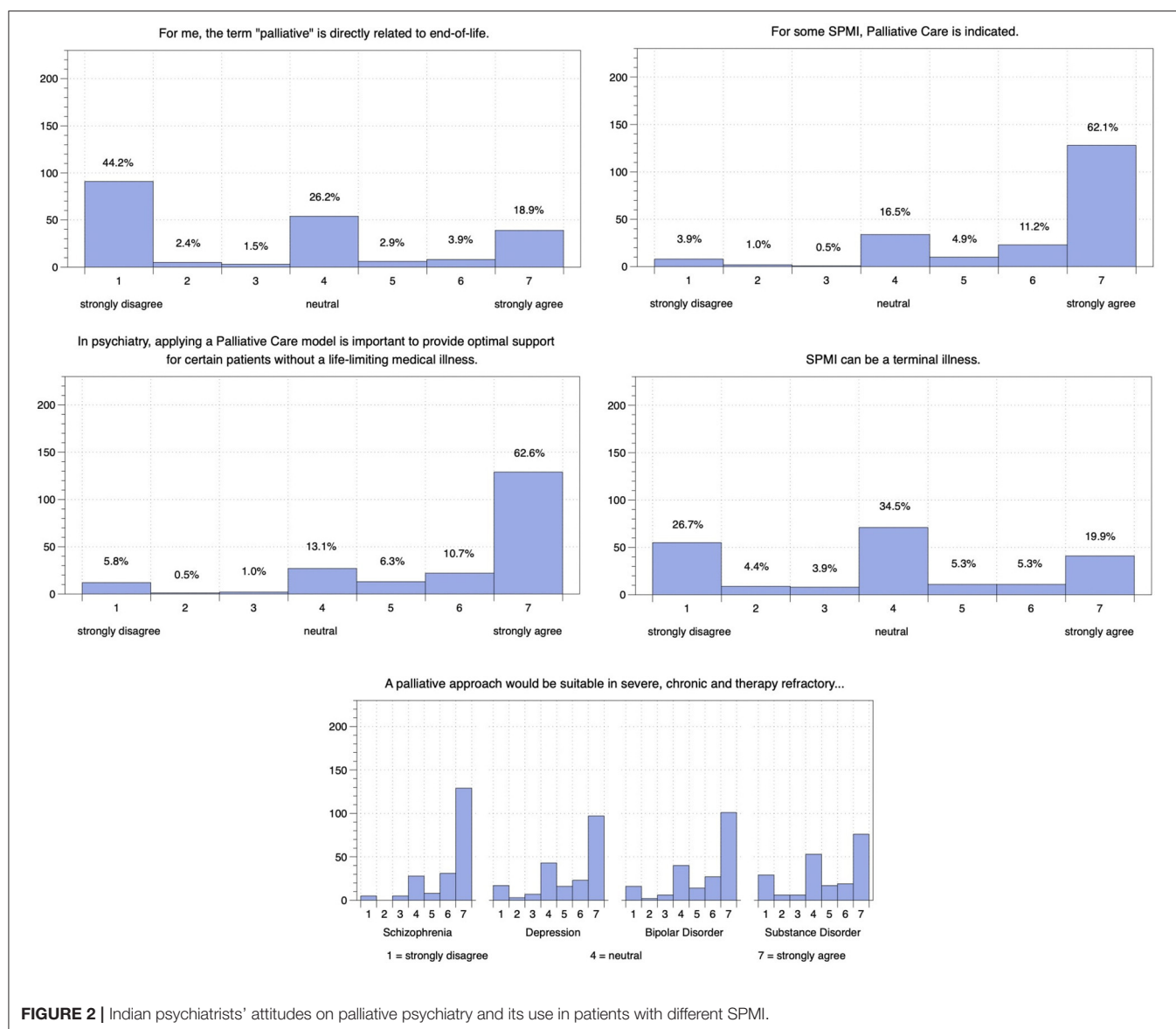
## Responses to the Case Vignettes Schizophrenia

Overall, 42.7% of respondents agreed that *further curative intervention would probably be futile in this case of schizophrenia* while 29.1% disagreed and 28.2% remained neutral (see **Figure 3**). 40.8% indicated that they would not be comfortable with a *reduction in life expectancy to increase or maintain the patient's quality of life* while 32.0% indicated they would be comfortable with this and 27.2% remained neutral. When asked whether they would be *surprised if the patient died within the next 6 months*, 41.7% agreed while 41.3% remained neutral and only 17.0% disagreed.

## Recurrent Major Depressive Disorder

Most respondents (45.1%) disagreed that *further intervention to cure the patient's depression would probably be futile* while 32.0% remained neutral and 22.8% agreed (see **Figure 3**). While 40.3% would not be comfortable with a *reduction of life expectancy to increase or maintain the quality of life of this patient*, 31.1% said they would be, and 28.2% remained neutral. Finally, 38.3% of





**FIGURE 2 |** Indian psychiatrists' attitudes on palliative psychiatry and its use in patients with different SPMI.

respondents said they would not be *surprised if the patient died within the next 6 months* while 35.9% remained neutral and 25.7% said they would be surprised.

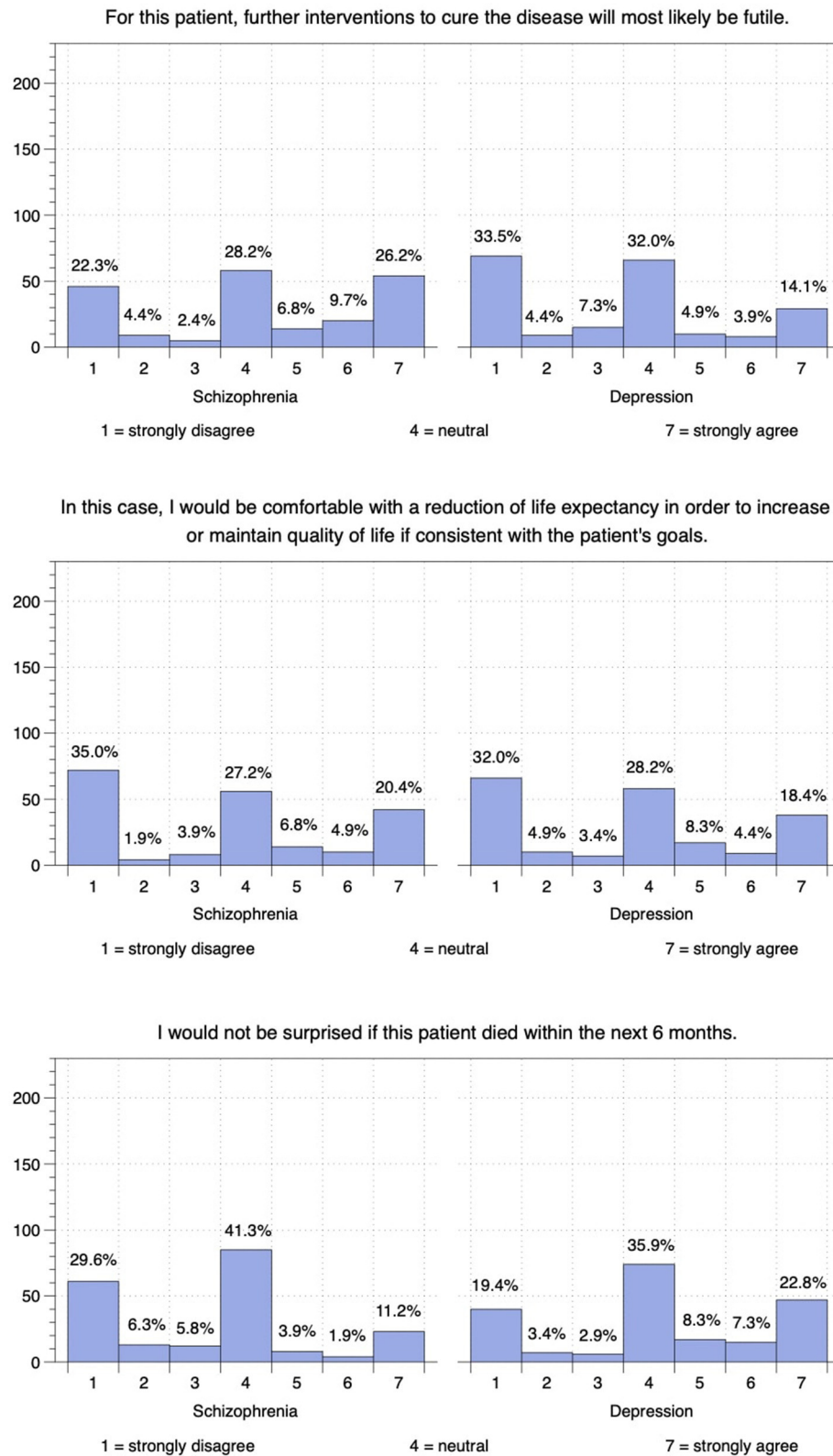
## Comparison of Psychiatrists' Views in India and Switzerland

Psychiatrists in India agreed significantly less than psychiatrists in Switzerland that *SPMI can be a terminal illness* ( $U = 16244.0$ ,  $p < 0.001$ ,  $r = -0.55$ ; see **Table 2**), and considered it significantly more important to *impede suicide* when treating SPMI ( $U = 21310.0$ ,  $p < 0.001$ ,  $r = 0.48$ ; see **Table 2**). However, psychiatrists in India agreed significantly more than psychiatrists in Switzerland that *a palliative approach would be appropriate for patients with severe, chronic, and therapy-refractory schizophrenia* ( $U = 28897.5$ ,  $p < 0.001$ ,  $r = 0.32$ ).

Regarding the case vignette of a patient with severe and persistent schizophrenia, psychiatrists in India were significantly less comfortable than psychiatrists in Switzerland with a *reduction in life expectancy to increase or maintain quality of life* ( $U = 28752.0$ ,  $p < 0.001$ ,  $r = -0.31$ ; see **Table 2**). The same was true in the case of the patient with recurrent major depressive disorder ( $U = 28731.5$ ,  $p < 0.001$ ,  $r = -0.31$ ). In this case, psychiatrists in India also reported to a significantly greater extent that they would be surprised *if the patient died within the next 6 months* ( $U = 27121.5$ ,  $p < 0.001$ ,  $r = 0.34$ ).

## DISCUSSION

For a vast majority of psychiatrists in India, suicide prevention in patients with severe and persistent mental illness (SPMI) was very important. Psychiatrists in India also tended not to view



**FIGURE 3 |** Indian psychiatrists' attitudes on the case vignettes.

SPMI as a terminal illness with 26.7% even strongly disagreeing with this notion. However, curing the illness was not very important for the majority, and some psychiatrists in India even regarded further curative treatment as futile in specific cases. Almost all psychiatrists emphasized the importance of reducing suffering and improving functionality of SPMI patients in everyday life, both of which are central concepts in palliative psychiatry (8, 10) as a genuine biopsychosocial approach which systematically integrates biological, psychological, social, and existential factors of care (12, 13). Consecutively, a majority believed that palliative psychiatry is indicated for some patients with SPMI (especially schizophrenia), even in the absence of a life-limiting somatic disease. However, when confronted with vignettes of specific patients with severe, chronic, and therapy-refractory schizophrenia and depression, most psychiatrists in India indicated that they would not be comfortable with improving quality of life at the expense of life expectancy.

At first glance, this strong emphasis on both duration and quality of life of SPMI patients may be difficult to reconcile. However, palliative psychiatry can be accommodated alongside a curative approach, and as the disorder does not need to be terminal for the application of palliative psychiatry (8), it does not necessarily mean discontinuing curative treatment (6). In line with this interpretation, only a minority of surveyed psychiatrists in India found that the term palliative directly relates to end of life.

## Comparison of Psychiatrists' Attitudes in India and Switzerland

The participating psychiatrists in India tended to support both curative and palliative approaches for patients with SPMI more strongly than psychiatrists in Switzerland. Regarding curative approaches, psychiatrists in India considered it more important to impede suicide and to cure patients with SPMI than psychiatrists in Switzerland. In line with these attitudes, psychiatrists in India were less likely to believe that SPMI can become a terminal illness. The same trend is apparent in both case vignettes; psychiatrists in India would be more surprised if the patient with severe and persistent schizophrenia or recurrent major depressive disorder would die within the next 6 months. They were less likely to consider further intervention futile in both cases than psychiatrists in Switzerland, and they would not be comfortable with a reduction of life expectancy in either case, even at the expense of quality of life.

How might we explain the stronger support for curative approaches and suicide prevention in SPMI of psychiatrists in India? First, as referred to in the introduction, it is considered important not to classify patients as chronic or therapy-refractory because of insufficient treatment and resources; on that basis, a curative approach should not be abandoned (6). As psychiatrists in India are likely very aware of this issue, they may therefore tend to favor a curative approach even for patients classified as suffering from chronic, severe, and therapy-refractory mental disorders.

Second, although suicide rates in India are generally comparable to Switzerland (33), in persons aged between 15

and 49, suicide rates in India are almost twice as high as in Switzerland (34). Vijayakumar (35) reported that more than 70% of suicides in India involve persons younger than 44, which is the age range in the case vignettes. In a comparative study of attitudes to suicide among medical students in India and Austria, overall attitudes were more negative in India, and suicide was associated with mental illness, cowardice, and even illegality (36). In India, attempted suicide was only recently decriminalized in the Mental Health Care Act of 2017 (37). Indian medical students also exhibit a strong aversion to physician-assisted suicide (36). In contrast, physician-assisted suicide has been legal for decades in Switzerland, and the psychiatrists surveyed in Switzerland supported the idea for patients with SPMI to some extent (26).

Third, while it might seem interesting to explore whether these differences in pro-life attitude relate to religious beliefs, Etzersdorfer et al. (36) found no evidence that religion played a role in the differing attitudes to suicidal behavior of medical students from India and Austria. Referring primarily to the Hindu religion, they found no greater aversion to suicide than in the Christian religion and further noted that there is some evidence of institutionalized suicide in India. In a more recent questionnaire study, Thimmaiah et al. (38) reported that negative attitudes to suicidality are less common among Hindus than Muslims, and these cultural differences invite further research.

Besides the greater support for curation and suicide prevention, psychiatrists in India also assigned greater importance to the reduction of suffering and functionality in daily life than their counterparts in Switzerland. They agreed more strongly that palliative approaches might be indicated in patients with SPMI, even in the absence of life-limiting disease.

By implication, the participating psychiatrists in India tended to support both curative and palliative approaches for patients with SPMI. This suggests that, for psychiatrists in India, curative approaches and palliative psychiatry are not mutually exclusive but can complement each other to alleviate suffering and increase functionality in daily life in parallel to curative treatments (8). Such a notion of compatibility of palliative psychiatry and curative approaches may be facilitated by regarding the term *palliative* as not directly related to the end of life, which psychiatrists in India were significantly more likely to do than psychiatrists in Switzerland.

## Strengths and Limitations of the Study

One limitation of the study is the low response rate of 6.7% in the Indian sample (compared to a response rate of 34.9% in the Swiss sample). Basing the calculation on the population who clicked on the link yields a response rate of 36.7%. The generalizability of the data may therefore be limited as the participants are likely to have an existing interest in SPMI and palliative care. However, there is evidence that non-response bias may be of less concern in physician surveys than in surveys of other populations (39). Also, response rates are known to be lower in online surveys (40) and in surveys of physicians (39), especially psychiatrists (41).

As only psychiatrists were surveyed, the generalizability of the response patterns to other professions is limited.

The observed differences between the two samples might relate to differences in age and career duration. It is also

**TABLE 2 |** Comparison of India and Switzerland.

Item	Group	<i>n</i>	<i>M</i>	<i>Mdn</i>	<i>U</i>	<i>Z</i>	<i>p-value</i>	<i>r</i>
Ia: curing the illness	India	206	4.73	4	32431.0	−6.27	<0.001***	−0.25
	Switzerland	447	3.73	4				
	Total	653						
Ib: reduction of suffering	India	206	6.87	7	38091.5	−5.64	<0.001***	−0.22
	Switzerland	456	6.66	7				
	Total	662						
Ic: function in daily life	India	206	6.74	7	39209.0	−4.42	<0.001***	−0.17
	Switzerland	456	6.55	7				
	Total	662						
Ie: impeding suicide	India	206	6.84	7	21310.0	−12.38	<0.001***	−0.48
	Switzerland	454	5.80	6				
	Total	660						
If: term “palliative”	India	206	3.29	4.00	34116.0	−5.58	<0.001***	−0.22
	Switzerland	452	4.24	4.00				
	Total	658						
Ig: SPMI and palliative care	India	206	6.00	7.00	31241.5	−6.75	<0.001***	0.26
	Switzerland	444	5.39	6.00				
	Total	650						
Ih: Palliative care support (not life-limiting)	India	206	5.96	7.00	32133.5	−6.53	<0.001***	0.26
	Switzerland	449	5.43	6.00				
	Total	655						
Ii: SPMI can be terminal	India	206	3.83	4.00	16244.0	−14.22	<0.001***	−0.55
	Switzerland	453	6.36	7.00				
	Total	659						
Ij: schizophrenia (palliative approach)	India	206	6.12	7.00	28897.5	−8.10	<0.001***	0.32
	Switzerland	452	5.24	6.00				
	Total	658						
Ik: depression (palliative approach)	India	206	5.40	6.00	37811.0	−3.96	<0.001***	0.15
	Switzerland	452	5.00	6.00				
	Total	658						
Il: bipolar disorder (palliative approach)	India	206	5.52	6.00	35209.0	−5.14	<0.001***	0.20
	Switzerland	452	4.94	6.00				
	Total	658						
Im: substance disorder (palliative approach)	India	206	4.86	5.00	43921.5	−1.19	0.233	−0.05
	Switzerland	452	5.26	6.00				
	Total	658						
(1) Schizophrenia								
IIb: futility of further intervention	India	206	4.27	4	40541.5	−2.53	0.011*	−0.10
	Switzerland	448	4.82	5				
	Total	654						
IIc: quality of life vs. reduction of life expectancy	India	206	3.65	4	28752.0	−7.88	<0.001***	−0.31
	Switzerland	448	5.15	5				
	Total	654						
IIe: dying within the next 6 months (surprise question)	India	206	3.34	4				

(Continued)



TABLE 2 | Continued

Item	Group	<i>n</i>	<i>M</i>	<i>Mdn</i>	<i>U</i>	<i>Z</i>	<i>p-value</i>	<i>r</i>
(2) Depression	Switzerland	450	4.39	4	31333.5	−6.80	<b>&lt;0.001***</b>	−0.27
	Total	656						
IIb: futility of further intervention	India	206	3.38	4	32672.0	−6.14	<b>&lt;0.001***</b>	−0.24
	Switzerland	450	4.41	5				
IIc: quality of life vs. reduction of life expectancy	Total	656			28731.5	−7.87	<b>&lt;0.001***</b>	−0.31
	India	205	3.63	4				
Ile: dying within the next 6 months (surprise question)	Switzerland	450	5.05	5	27121.5	−8.76	<b>&lt;0.001***</b>	−0.34
	Total	655						
	India	206	4.23	4				
	Switzerland	450	5.71	6				
	Total	656						

Only abbreviated questionnaire items are shown [see **Supplementary Material** for complete list of items]. *r*: effect size [for calculation see citations (31, 32)]. Significant *p* values (*p* < 0.05) in bold: \*\*\**p* < 0.001, \**p* < 0.05.

important to note that response behavior can vary across countries and cultures (42), which may be compounded by the fact that the questionnaires were presented in different languages (German and English). For example, the psychiatrists in India (up to 30%) chose the middle category more often than those in Switzerland. To limit and identify any interpretive bias associated with dichotomous significance testing, effect sizes were also calculated.

Other general limitations of this type of survey have already been mentioned in previous studies based on the same questionnaire (9, 26, 27) but can be briefly summarized as follows. First, a Likert scale can only reflect the opinions of individuals to a limited extent and cannot fully capture the complexity of the topic. Importantly, we did not assess how the individual participants conceptualize palliative psychiatry. Second, the case vignettes represent highly specific cases and are not representative of the respective disorders in general.

## Implications for Clinical Practice and Future Research

The hesitation to integrate palliative psychiatry in existing mental healthcare structures may reflect the fact that it is too often associated with end of life, giving up, and hopelessness (2, 3, 7). The present findings and particularly the views of psychiatrists in India suggest that first, palliative psychiatry is considered valuable across cultures as a means of improving patients' quality of life, without necessarily accepting a reduction in life expectancy, and second, rather than asking "palliative or curative?," we should discuss the possibility of palliative and curative, combining both approaches to offer optimal treatment to patients with SPMI. As Strand and colleagues (7) have argued, "[...] the type of interventions referred to as palliative are by no means 'novel' and 'cutting-edge'—quite the contrary, we interpret palliative care as an approach defined by its goals and not by the use of specific treatments" (p. 6). It seems important, then, that

researchers and clinicians focus on developing a framework for clinical practice that optimally combines curative and palliative approaches for the individual patient and situation.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethics Committee, Government Medical College, Thiruvananthapuram (HEC.No.01/06/2020/MCT, dated 07.02.2020). The patients/participants provided their written informed consent to participate in this study.

## AUTHOR CONTRIBUTIONS

AM, CV, AP, and MT conceived the study and were involved in adapting the questionnaire for data collection in India. AM, CV, JS, and MT were involved in data collection. JS, MT, and AW evaluated the data and drafted the article. All authors were involved in critical revision of the draft manuscript and all approved the final version submitted for publication.

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## SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpsy.2022.858699/full#supplementary-material>

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# Analysis of Real-World Implementation of the Biopsychosocial Approach to Healthcare: Evidence From a Combination of Qualitative and Quantitative Methods

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**Aims:** The modern medical model has been transformed into a biopsychosocial model. The integration of the biopsychosocial approach in healthcare can help improve the effectiveness of diagnosis and treatment. This study explored the actual application of the biopsychosocial approach in healthcare and provides a basis for targeted interventions to promote the biopsychosocial approach in healthcare.

**Methods:** Study 1 involved one-on-one interviews with 30 medical staff and focus group interviews with 16 recent patients. Study 2 was a cross-sectional survey of 13,105 medical staff in Hangzhou, China that analyzed the status quo implementation of the biopsychosocial approach in healthcare.

**Results:** Study 1 found that medical staff did not welcome patients to report information unrelated to their disease, hoping patients did not express their emotions. In the treatment process, patients believed that medical staff refused to attend to or did not encourage reporting of any information other than the disease, and that patients should have reasonable expectations for medical staff. Study 2 found that medical staff had a 37.5% probability of actively paying attention to the patient's psychosocial status. Female medical staff (38.5%) were actively concerned about the patient's psychosocial status significantly more than male medical staff (34.2%) ( $P < 0.01$ ). The medical staff in the psychiatric department (58.4%) paid more active attention to the patient's psychosocial status than staff in the non-psychiatric departments (37.2%). Gender, department, hospital level, and professional title were the factors associated with the medical staff's attention to the patient's psychosocial status ( $P < 0.05$ ). The influence of age on the probability of medical staff actively paying attention to the psychosocial status of patients increased with the number of years of employment. Participants that were 31–40 years old, had an intermediate professional title, and 11–15 years of employment were the least likely to actively pay attention to patients' psychosocial status.



**Conclusion:** Although the biopsychosocial approach has been popularized for many years, it has not been widely used in medical care. Medical staff pay more attention to patients' physical symptoms and less attention to patients' psychosocial status. It is recommended that training will be provided to medical personnel on implementing a biopsychosocial approach with particular attention to the sociodemographic characteristics of medical personnel. Additionally, we propose helping patients set reasonable expectations, and formulating guidelines for implementing the biopsychosocial approach.

**Keywords:** biopsychosocial approach, healthcare, medical staff, psychosocial status, qualitative and quantitative methods

## INTRODUCTION

With the changes in the spectrum of human diseases, understanding psychological disorders and symptoms continue to deepen. People have become increasingly aware that no single reason could cause the appearance of symptoms, and psychological and social factors need to be considered. Therefore, a purely biomedical model cannot serve and meet the needs of contemporary medical care. In 1977, Engel (1) pointed out the limitations of the biomedical model, integrated psychological and social dimensions, and proposed a biopsychosocial approach. Engel held the view that disease is the result of the interaction of biological, psychological, and social subsystems on multiple levels and highlighted the indispensable role of psychosocial factors, which explained such phenomena as the effect of living conditions on the development of the disease. The premise of the biopsychosocial approach is that the patient's disease cannot be divorced from his or her psychosocial causes, personality, and surroundings (2). Evidence has shown that social/environmental and psychological factors matter in the development of psychiatric disorders (3). In the following decades, the biopsychosocial approach was mentioned in many disciplines and practical fields, including medical traumatic stress, anorexia nervosa, addiction treatment, daily pain, elderly frailty, disability, and health psychology (4–10). With the recognition that some risk factors of the disease are psychosocial rather than biomedical, and that some non-pharmacologic and non-surgical treatment modalities have a therapeutic effect, the biopsychosocial approach potentially improves clinical outcomes for chronic diseases and functional illnesses seen in primary care (11). The biopsychosocial approach in healthcare can improve the effectiveness of diagnosis and treatment (12), which enhances patient satisfaction and can ease conflicts between doctors and patients.

In clinical training such as medical schools and graduate schools, the biopsychosocial approach has been widely taught to arouse attention to the interaction between various factors that affect health and cause diseases (13). However, integrating the biopsychosocial approach into healthcare practice has not been as successful as integrating the approach into research and medical education (14). Most modern healthcare is still based on the biomedical model of disease, which can help identify and

treat many diseases. However, it has difficulty recognizing the multi-factor and complexity of many (including non-organic) diseases. In addition, it is easy to ignore the psychosocial status of patients, which may trigger unnecessary disease behaviors in patients (15). Although the biomedical model promotes many healthcare innovations, a biomedical perspective alone cannot guarantee favorable results, nor can it explain the placebo effect and health gaps. It must also include psychological and social factors (10). Suls and Rothman (16) proposed that applying the biopsychosocial framework has not been fully utilized and should be considered in health psychology theories and clinical practice. Fava and Sonino (17) pointed out that although the biopsychosocial framework has been implemented for many years and the evidence base has grown over time, the implementation of this framework in healthcare has been slow. According to Adler (14), studies have found that many medical staff, such as the staff in pain clinics and on medical psychiatric wards, do not adhere to Engel's biopsychosocial approach. The application of the biopsychosocial approach needs thorough evaluation of the psychological, behavioral, sociocultural, and spiritual dimensions of patients' problems, which is time-consuming (18). For physicians who are already overburdened with clinical, administrative, and possibly research tasks, it is a formidable task (11).

However, as diseases become more complicated and multi-factorial, studying the status quo implementation of the biopsychosocial approach has far-reaching significance in health care. Surprisingly, we know very little about the practical application of the biopsychosocial approach in healthcare. To fill this gap in the literature, we explored the practical application of the biopsychosocial approach in healthcare through qualitative and quantitative research methods. Qualitative research in this area can provide us with valuable and comprehensive information and deepen our understanding of the practical application of the biopsychosocial approach in healthcare. Carrying out large-scale quantitative research complements the qualitative data, by investigating and analyzing the current status of implementing the biopsychosocial approach in healthcare and related factors. The knowledge gained would provide a scientific basis for how to carry out effective interventions to promote the status quo implementation of the biopsychosocial approach in healthcare. Specifically, the study could serve as a reference and

provide direction for promoting doctor-patient communication; improving patient participation, acceptance, and compliance; improving the effectiveness of diagnosis and treatment; and promoting the harmony in the doctor-patient relationship.

The primary purpose of this study was to explore the implementation of biopsychosocial approach in healthcare and any differences associated with the psychosocial status of patients with different sociodemographic variables. One important factor is the gender of the medical professional. During the consultation process, female doctors have been shown to provide a longer consultation time than male doctors (19). In addition, women were found to use more emotion-focused coping strategies than men (20). Therefore, female doctors may pay more attention to patients' emotions and social factors. Thus, we examined the following hypothesis.

H1: Female medical staff pay more attention to the psychosocial status of patients than male medical staff.

The organizations in which people work affect their thoughts, feelings, and actions in the workplace (21). Hence, the difference in working environments may affect the thoughts and behaviors of medical staff. In a psychiatric department, because the working environment involves patients with mental illness, psychiatric staff may pay more attention to the psychosocial status of patients than in an environment where the medical staff are working with non-psychiatric patients. Therefore, we examined the following hypothesis.

H2: Psychiatric medical staff pay more attention to the psychosocial status of patients than non-psychiatric medical staff.

In China, hospitals are divided into three levels according to their functions and tasks (22). The first-level hospitals provide the community with primary healthcare, prevention, rehabilitation, and health care services. The second-level hospital is responsible for providing diagnosis and treatment of common and frequently occurring diseases for the community. The tertiary hospital is a comprehensive medical institution that provides specialized medical services (23). Medical staff at different hospital levels face different workloads, different kinds or parts of training, and different working environments, which may affect their attention to the psychosocial status of patients. Among them, tertiary hospitals provide diagnosis and treatment services for acute, critical, and difficult and complex diseases, which require comprehensive evaluation of patients. As such, medical staff in tertiary hospitals may pay more attention to the psychosocial status of patients than medical staff in secondary hospitals and first-level hospitals. Consequently, we proposed the following hypothesis.

H3: Medical staff in tertiary hospitals pay more attention to the psychosocial status of patients than medical staff in first- and second-level hospitals.

Lastly, it has been shown that burnout symptoms among doctors are prevalent and associated with age, professional title, and long working hours (24). Age and years of employment are

related to the psychosocial workload of medical staff (25), which may affect the attention of medical staff to the psychosocial status of patients. Medical staff may face pressure from job tasks and their promotion to professional titles, and the professional title may affect their attention to the psychosocial status of patients. Medical staff with senior professional titles may pay more attention to the psychosocial status of patients. However, medical staff with junior and intermediate titles are faced with heavy workloads and the pressure to be promoted. Therefore, they may pay less attention to the psychosocial aspects of patients. Given these differences, our last hypothesis was as follows:

H4: Medical staff's attention to patients' psychosocial status will be associated with their age, years of employment, and professional title.

## MATERIALS AND METHODS

### Design and Participants

This research study used a combination of qualitative and quantitative research methods. Study 1 conducted one-on-one interviews with 30 medical staff and conducted focus group interviews with 16 recent patients to summarize the views of both doctors and patients on the biopsychosocial approach. Participants in the one-on-one interviews were selected through random sampling from medical staff in the outpatient and ward areas of a large tertiary hospital in Zhejiang, China in September 2019. The researcher introduced himself to the interviewees who met the inclusion criteria and explained the purpose and methods of the study. After obtaining consent, the interview was conducted according to a semi-structured interview outline determined in advance. The interview began by asking for basic information on the participant, such as department and years of employment, which was followed by the interview questions, such as "What information do you want the patient to tell you when you are providing treatment?" and "What about the patient's behavior do you think will hinder the diagnosis and treatment?" The participants included 13 men and 17 women. Their average working experience was  $9.84 \pm 8.08$  years and they were from diverse medical fields (e.g., internal medicine, urology, endocrinology).

Two focus group interviews were conducted in June 2020, and each group included eight participants. A semi-structured interview outline was prepared in advance for the purposes of the group interview, which asked the participants to "Please talk about your most recent medical experience," and questions such as "During the treatment, what behaviors or reactions do you think will promote or hinder the medical treatment process?" Inclusion criteria for the focus group were clear verbal expression and medical experience in the past 6 months. The participants were 6 men and 10 women with an average age of  $22.9 \pm 2.11$  years. The researcher introduced himself to the patients who met the inclusion criteria and explained the purpose and methods of the research. The researcher obtained informed consent from each participant before conducting the focus group. Focus group interviews were recorded and the researcher took notes.

**TABLE 1** | The descriptive characteristics of the participants.

Demographic characteristics	<i>n</i> (%)	<i>M</i>	<i>SD</i>	<i>t</i>	<i>P</i>
<b>Gender</b>					
Male	3,084 (23.5)	34.2	30.4	−6.8	0.00
Female	10,021 (76.5)	38.5	31.0		
<b>Department</b>					
Psychiatric	206 (1.6)	58.4	33.1	−9.8	0.00
Non-psychiatric	12,899 (98.4)	37.2	30.8		
<b>Hospital level</b>					
Tertiary hospital	2,681 (20.5)	42.6	32.6	94.5	0.00
Second-level hospital	5,064 (38.6)	39.2	31.3		
First-level hospital	5,360 (40.9)	33.3	29.2		
<b>Professional title</b>					
Junior	6,662 (50.8)	40.1	31.9	35.5	0.00
Intermediate	4,627 (35.3)	34.1	29.5		
Deputy Senior	1,412 (10.8)	36.5	30.1		
Senior	404 (3.1)	37.8	30.6		
<b>Age</b>					
20–30 years	3,614 (27.6)	42.4	32.1	53.3	0.00
31–40 years	5,466 (41.7)	34.3	30.0		
41–50 years	3,018 (23.0)	36.4	30.4		
>50 years	1,007 (7.7)	40.6	31.0		
<b>Years of employment</b>					
0–5 years	2,567 (19.6)	43.1	32.1	34.9	0.00
6–10 years	2,603 (19.9)	37.6	31.3		
11–15 years	3,305 (25.2)	33.8	30.0		
16–20 years	1,289 (9.8)	35.4	30.0		
>20 years	3,341 (25.5)	37.6	30.4		

The *M* and *SD* in this table are the mean and its associated standard deviation of the probability of medical staff actively paying attention to the patient's psycho-social state.

From December 2020 to January 2021, Study 2 was carried out in Hangzhou, Zhejiang Province. An anonymous online questionnaire was used to gather data on the current status of implementing the biopsychosocial approach in healthcare. The questionnaire asked for demographic information including gender, department, hospital level, professional title, age, years of employment, and the probability of actively paying attention to the patients' psychosocial status. To assess the probability of medical staff actively paying attention to the patient's psychosocial status, participants were asked, "During the consultation process, in (%) of the cases, I will actively pay attention to the patient's psychosocial status rather than just the physical symptoms." A total of 13,105 medical staff were surveyed.

**Table 1** shows detailed information on the participants' characteristics. Of the 13,105 eligible medical staff that were included in this study, 23.5% ( $n = 3,084$ ) were men and 76.5% ( $n = 10,021$ ) were women. A total of 1.6% ( $n = 206$ ) were psychiatric medical staff and 98.4% ( $n = 12,899$ ) were non-psychiatric. There were 2,681 (20.5%) medical staff from tertiary hospitals, 5,064 (38.6%) medical staff from second-level hospitals, and 5,360 (40.9%) medical staff from first-level hospitals. Approximately half (50.8%) of the medical staff had junior titles and 4,627 (35.3%) had intermediate titles. In terms

of age, 27.6% ( $n = 3,614$ ) were ages 20–30, 41.7% ( $n = 5,466$ ) were 31–40, 20.3% ( $n = 3,018$ ) were 41–50, and 7.7% ( $n = 1,007$ ) were ages 51 or older. With regard to years of employment, 19.6% ( $n = 2,567$ ) were employed 0–5 years, 19.9% ( $n = 2,603$ ) 6–10 years, 25.2% ( $n = 3,305$ ) 11–15 years, 9.8% ( $n = 1,289$ ) 16–20 years, and 25.5% ( $n = 3,341$ ) were employed for 21 years or more.

## Statistical Analyses

In Study 1, we used thematic analysis to analyze the qualitative data. Initially, we transcribed the recorded interview then reviewed the transcribed data three times to obtain a general understanding. Next, we extracted semantic units and classified them as compact units. We then honed the important parts of each unit and what aspects of the qualitative data it covered. Next, the compact unit was further summarized and marked with appropriate headings. In addition, we searched for overlapping areas between topics, identified emerging subtopics, provided more detailed topic descriptions and described the hierarchical structure in the data, and clearly defined the scope of each topic. Finally, the sub-categories were grouped according to similarities and differences, and appropriate titles that could represent the resulting categories were selected.

In Study 2, we analyzed the sociodemographic variables and calculated the number and percentage distribution of

the categorical variables. The independent *t*-test and one-way analysis of variance were used to determine sociodemographic differences among medical staff with regard to actively paying attention to patients' psychosocial status. Lastly, all variables were included in a stepwise linear regression model (the entry/clearance criterion was  $P = 0.05/0.1$ ) for analysis. All statistical analyses were performed using IBM SPSS Version 26.0, and  $P < 0.05$  (two-tailed) was considered statistically significant.

## RESULTS

### Study 1

#### Medical Staff Do Not Welcome Patients to Report Information That Is Not Related to the Disease

During the consultation process, some medical staff paid more attention to the patient's physical symptoms. Patients were not welcome to report information that was not related to the disease. Medical staff hoped that the patient would grasp the key points when explaining their condition.

"The patients only need to talk about the disease and what is related to the disease during the communication with medical staff, and not mention other content." (A male orthopedic doctor who has worked for 10 years)

"During the treatment, the patient does not need to say too much that has nothing to do with the symptom." (A female doctor in the urology department who has worked for 7 years)

"I hope that the patient's parents can accurately provide the child's medical history and clearly describe the condition." (A female neonatologist who has worked for 7 years)

"The patient should focus on the critical points in the process of describing the condition." (A female internal medicine outpatient doctor who has worked for 1 year)

#### Medical Staff Hope That Patients Will Not Confide in Them

The medical staff said that although they can understand the patients' mood, they hoped that the patient would not confide their emotions to them and that they need to maintain a rational attitude.

"Although the patient's mood is understandable, the patient does not need to say many things that have nothing to do with the patient's condition and only need to answer my questions accurately." (A respiratory physician who has worked for 9 years)

"I hope that the patients will not confide their emotions to the medical staff." (A female doctor in the gastroenterology department who has worked for 3 years)

"The patient's anxiety is understandable, but the patient should maintain a rational attitude during the treatment process." (A female doctor in the endocrinology department who has worked for 8 years)

#### The Patient Felt That Medical Staff Refused to Pay Attention to the Patient's Psychosocial Status

Some patients expressed their desire to get the attention of medical staff, thinking that the medical staff refused to pay attention to the patient's psychosocial status, which made patients feel dissatisfied.

"I want to describe my symptoms perfectly to the medical staff, but the medical staff seems to know me well, and the medical staff do not let me say too much. I feel a little dissatisfied. I want to talk to the medical staff, but the medical staff refuse to understand me." (Patient Y, male)

"The patients are eager to get the kind of attention from the medical staff. But if there is no particular situation, the medical staff will not pay attention to the patient deliberately." (Patient Z, female)

"I feel obstructed when communicating with some doctors, and the doctors may not listen carefully to what I say." (Patient C, female)

#### Patients Should Have Reasonable Expectations for Medical Staff

Most doctors believed that patients' high expectations would impact the effectiveness of diagnosis and treatment, so patients should have reasonable expectations. Some patients held the view that the patient's expectations for medical staff should be reasonable.

"Excessive expectations of patients have an impact on the effectiveness of diagnosis and treatment. I hope patients have reasonable expectations." (A male dentist who has worked for 7 years)

"Medical staff have as part of their responsibilities to take care of patients' emotions, but do not expect clinical medical staff to comfort patients like psychological medical staff." (Patient A, female)

"Patients are emotionally sensitive, which may hinder the doctor's diagnosis and treatment. Sometimes patients need to control their emotions and calm their minds to some extent." (Patient D, female)

### Study 2

#### Comparison of the Probability of Medical Staff Actively Paying Attention to the Psychosocial Status of Patients

There were significant differences in the probability of actively paying attention to the psychosocial status of patients according to gender, department, hospital level, professional title, age, and years of employment ( $P < 0.01$ ). Female medical staff (38.5%) were more likely to pay attention to the psychosocial status of patients than male medical staff (34.2%) ( $P < 0.01$ ). The medical staff in the psychiatry department (58.4%) paid more attention to patients' psychosocial status than the medical staff in other departments (37.2%).

**Table 2** provides the results of the comparisons according to hospital level, professional title, age, and years of employment. The probability of medical staff in second-level and tertiary hospitals actively paying attention to the psychosocial status of patients was significantly higher than that of medical staff in first-level hospitals, and medical staff in tertiary hospitals were more likely to pay attention to psychosocial status than medical staff in second-level hospitals.

The probability of medical staff 20–30 years old actively paying attention to the patient's psychosocial status was significantly higher than that of medical staff 31–40 years old and those



**TABLE 2 |** Comparison of medical staff in different demographic characteristics actively paying attention to the psycho-social state of patients.

Demographic characteristics		Mean difference (I-J)	SE	P	CI
<b>Hospital level</b>					
Tertiary hospital	Second-level hospital	3.5	0.8	0.00	(1.66, 5.26)
	First-level hospital	9.3	0.8	0.00	(7.56, 11.06)
Second-level hospital	Tertiary hospital	-3.5	0.8	0.00	(-5.26, -1.66)
	First-level hospital	5.9	0.6	0.00	(4.46, 7.25)
First-level hospital	Tertiary hospital	-9.3	0.8	0.00	(-11.06, -7.56)
	Second-level hospital	-5.9	0.6	0.00	(-7.25, -4.46)
<b>Professional title</b>					
Junior	Intermediate	6.0	0.6	0.00	(4.49, 7.49)
	Deputy Senior	3.6	0.9	0.00	(1.31, 5.90)
	Senior	2.3	1.6	0.45	(-1.73, 6.37)
Intermediate	Junior	-6.0	0.6	0.00	(-7.49, -4.49)
	Deputy Senior	-2.4	0.9	0.04	(-4.73, -0.05)
	Senior	-3.7	1.6	0.09	(-7.75, 0.41)
Deputy Senior	Junior	-3.6	0.9	0.00	(-5.90, -1.31)
	Intermediate	2.4	0.9	0.04	(0.05, 4.73)
	Senior	-1.3	1.7	0.88	(-5.71, 3.15)
Senior	Junior	-2.3	1.6	0.45	(-6.37, 1.73)
	Intermediate	3.7	1.6	0.09	(-0.41, 7.75)
	Deputy Senior	1.3	1.7	0.88	(-3.15, 5.71)
<b>Age</b>					
20-30	31-40	8.1	0.7	0.00	(6.37, 9.81)
	41-50	6.1	0.8	0.00	(4.07, 8.02)
	>50	1.8	1.1	0.36	(-1.05, 4.68)
31-40	20-30	-8.1	0.7	0.00	(-9.81, -6.37)
	41-50	-2.0	0.7	0.02	(-3.81, -0.28)
	>50	-6.3	1.1	0.00	(-9.00, -3.55)
41-50	20-30	-6.1	0.8	0.00	(-8.02, -4.07)
	31-40	2.0	0.7	0.02	(0.28, 3.81)
	>50	-4.2	1.1	0.00	(-7.12, -1.34)
>50	20-30	-1.8	1.1	0.36	(-4.68, 1.05)
	31-40	6.3	1.1	0.00	(3.55, 9.00)
	41-50	4.2	1.1	0.00	(1.34, 7.12)
<b>Years of employment</b>					
0-5	6-10	5.54	0.9	0.00	(3.14, 7.95)
	11-15	9.3	0.8	0.00	(7.10, 11.58)
	16-20	7.7	1.1	0.00	(4.83, 10.57)
	>20	5.6	0.8	0.00	(3.33, 7.83)
6-10	0-5	-5.5	0.9	0.00	(-7.95, -3.14)
	11-15	3.8	0.8	0.00	(1.59, 5.99)
	16-20	2.2	1.0	0.23	(-0.68, 4.99)
	>20	0.0	0.8	1.00	(-2.17, 2.24)
11-15	0-5	-9.3	0.8	0.00	(-11.58, -7.10)
	6-10	-3.8	0.8	0.00	(-5.99, -1.59)
	16-20	-1.6	1.0	0.46	(-4.33, 1.06)
	>20	-3.8	0.7	0.00	(-5.78, -1.73)
16-20	0-5	-7.7	1.1	0.00	(-10.57, -4.83)
	6-10	-2.2	1.0	0.23	(-4.99, 0.68)
	11-15	1.6	1.0	0.46	(-1.06, 4.33)
	>20	-2.1	1.0	0.20	(-4.82, 0.58)
>20	0-5	-5.6	0.8	0.00	(-7.83, -3.33)
	6-10	-0.0	0.8	1.00	(-2.24, 2.17)
	11-15	3.8	0.7	0.00	(1.73, 5.78)
	16-20	2.1	1.0	0.20	(-0.58, 4.82)

The CI means a 95% probability that the confidence interval contains the overall mean. The probability of correct estimation is 0.95, and the probability of estimation error is 0.05.

**TABLE 3 |** Linear regression analysis of the probability of medical staff actively paying attention to the psycho-social state of patients.

Variable	$\beta$	SE	t	P	CI
Gender	0.054	0.645	6.081	0.000	(2.660, 5.190)
Department	0.071	2.155	8.214	0.000	(13.477, 21.926)
Hospital level	0.103	0.361	11.669	0.000	(3.507, 4.923)
Professional title	-0.039	0.443	-3.484	0.000	(-2.412, -0.675)
Age	-0.003	0.076	-0.154	0.877	(-0.161, 0.137)
Years of employment	-0.043	0.072	-1.941	0.052	(-0.282, 0.001)
Hospital level $\times$ Professional Title level	-0.017	0.448	-1.950	0.051	(-1.753, 0.005)
Age $\times$ Years of employment	0.106	0.003	10.391	0.000	(0.025, 0.036)

The  $\beta$  is the estimate resulting from an analysis performed on standardized variables, representing the effect of an independent variable on the dependent variable. The SE indicates the deviation between the actual value and the regression estimate due to sampling error. The t is the significance test value of the t-test of the regression coefficient. The CI means a 95% probability that the confidence interval contains the overall mean. The probability of correct estimation is 0.95, and the probability of estimation error is 0.05.

who were 41–50 years old. Medical staff aged 41–50 and over 50 were more likely to pay attention to the psychosocial status of patients than those who were 31–40. The medical staff over the age of 50 were more likely to actively pay attention to the psychosocial status of patients than those aged 41–50. Medical staff aged 31–40 were the least likely to pay attention to patients' psychosocial status.

The probability of medical staff with junior professional titles actively paying attention to the psychosocial status of patients was significantly higher than that of the medical staff with intermediate professional titles and deputy senior professional titles. The probability that medical staff with deputy senior professional titles and senior professional titles actively pay attention to the psychosocial status of patients was significantly higher than that of the medical staff with intermediate professional titles. Medical staff with intermediate professional titles were the least likely to pay attention to the psychosocial status of patients.

Medical staff who had worked for 0–5 years were more likely to actively pay attention to the psychosocial status of patients than other medical staff who had worked for more years. Medical staff who had worked for 6–10 years were more likely to pay attention to the psychosocial status of patients than those who had worked for 11–15 years. Medical staff who had worked for more than 21 years were more likely to pay attention to the psychosocial status of patients than those who had worked for 11–15 years. Medical staff who had worked for 11–15 years were the least likely to actively pay attention to the psychosocial status of patients.

### Regression Analysis on the Probability of Medical Staff Actively Paying Attention to the Psychosocial Status of Patients

In order to identify the statistical significant characteristics of medical staff who actively pay attention to the psychosocial status of patients, we first included all sociodemographic variables into the stepwise linear regression analysis. Gender was indexed as 0 = male, 1 = female. Then, considering the possible interaction between hospital level and professional title, and between age and

years of employment, we included the interaction terms “hospital level  $\times$  professional title” and “age  $\times$  years of employment” into the regression equation. The results are shown in **Table 3**. Gender [ $\beta = 0.05$ , CI (2.66, 5.19),  $P < 0.01$ ], department [ $\beta = 0.07$ , CI (13.48, 21.93),  $P < 0.01$ ], hospital level [ $\beta = 0.10$ , CI (3.51, 4.92),  $P < 0.01$ ], and professional title [ $\beta = -0.04$ , CI (-2.41, -0.68),  $P < 0.01$ ] were statistical significant predictors of the probability of medical staff actively paying attention to the psychosocial status of patients. Age and years of employment were not statistical significant. Age and working years cannot independently predict the probability of medical staff actively paying attention to the psychosocial state of patients. But the interaction of age and years of employment was statistical significant [ $\beta = 0.11$ , CI (0.03, 0.04),  $P < 0.01$ ]. The influence of age on the probability of medical staff actively paying attention to the psychosocial status of patients increased with the increase in years of employment. The interaction of hospital level and professional title level was not statistical significant.

## DISCUSSION

In this study, we explored the implementation of the biopsychosocial approach in healthcare through a combination of qualitative and quantitative research methods. Our focus was to understand the experience of medical staff and patients with regard to the attention given to the psychosocial status of patients, and determine what sociodemographic factors were associated with differences among medical staff in the active attention they give to patients' psychosocial status. One qualitative research finding was that medical staff do not welcome patients to report information unrelated to the disease and hope that patients will not confide in them. Quantitative research found that medical staff had a 37.5% probability of actively paying attention to the patient's psychosocial status. This shows that medical staff focus on the patient's physical symptoms and tend to ignore the patient's psychosocial status. Based on the sample in the present study, it can be concluded that the biopsychosocial approach is not sufficiently applied in healthcare.

Another finding from the qualitative study was that some patients held the view that medical staff refused to pay attention to the patients' psychosocial status. The patients were eager to get such attention from the medical staff, which is consistent with previous research results. Vinson found that patients increasingly wanted to interact emotionally with medical staff (26). In the eyes of patients, the medical staff take care of the patient's emotions to a certain extent, which helps patients to relax. Patients feel helpless and hopeless in the face of the disease, and medical staff play an essential role in providing support to patients (27). The integration of biopsychosocial methods in healthcare needs to be established within medical staff (14).

In addition, according to the results of the qualitative study, patients should have reasonable expectations of the medical staff. Patients who go to the hospital generally have expectations regarding the care that they will receive. These expectations range from a desire for information or psychosocial support to expectations for specific tests or treatments. Fulfillment of patients' expectations may influence health care utilization, affect patient satisfaction, and be used to indicate quality of care (28). Health care expectations may be positive or negative (29). Particular emphasis should be placed on patients with excessive expectations, as the lack of an achievable balance between expectations and fulfillment may lead to dissatisfaction (30). Therefore, in routine medical services, medical staff should discuss the treatment plan with patients and the realization of short- and long-term goals to ensure that patients' expectations are realistic and reasonable (31). Medical staff should actively listen to determine patients' understanding and concerns about the disease, respond to patients' concerns, and help set reasonable expectations, which is helpful to establish a harmonious doctor-patient relationship.

The quantitative study results verified our first hypothesis. Female medical staff (38.5%) were more likely to actively pay attention to the psychosocial status of patients than male medical staff (34.2%). Our findings are consistent with prior studies indicating that the gender of the doctor is a relevant factor in the differences in medical care provided. For example, it was found that female doctors take an average of 2 min longer to see a patient than male doctors (32), are more likely to ask patients about health risks and unhealthy behaviors and provide more psychological support (33).

In addition, department and hospital level were factors associated with medical staff actively paying attention to the psychosocial status of patients. Psychiatric medical staff actively paid more attention to the psychosocial status of patients than non-psychiatric medical staff. This verifies our hypothesis that psychiatrists would pay more attention to the psychosocial status of patients due to the particularity of the department. However, our results showed that only 58.4% of the psychiatric medical staff paid attention to the patient's psychosocial status. Regarding hospital level, medical staff in tertiary and second-level hospitals were more likely to actively pay attention to the psychosocial status than medical staff in first-level hospitals. To a certain extent, our results are consistent with Meretoja et al.'s (34) finding that competence profiles differed in both the level and infrequency of using competencies according to work

environment. There are differences in the work environments of hospitals of different levels, including the competence of the medical staff, which may affect the degree to which medical staff pay attention to the psychosocial status of patients.

The hypothesis that medical staff's active attention to patients' psychosocial status is related to age, years of employment, and professional title was also supported. Professional title and the interaction of age and years of employment had predictive effects on the probability of medical staff actively paying attention to the patient's psychosocial status. The influence of age increased with the increase in years of employment. We found that the medical staff aged 31–40 years, with an intermediate professional title, and 11–15 years of employment were least likely to actively pay attention to the patient's psychosocial status. Previous studies have found that age, working years, and work burden were essential predictors of job burnout for doctors and nurses (35). Compared with other occupations, occupational stress and burnout symptoms were more common among doctors (36). The job burnout of doctors was related to changes in the professional environment, such as financial pressure, increased workload, and index assessment (37). Therefore, we speculate that medical staff aged 31–40 with intermediate professional titles and 11–15 years of employment may have a heavier workload, more tremendous pressure for promotion, and face more severe job burnout. Thus, they have the lowest probability of actively focusing on the patient's psychosocial status.

Based on the findings mentioned above in this study, the biopsychosocial approach has not been widely used in healthcare. Most medical staff tend to only focus on the patients' physical symptoms and not pay attention to the patients' psychosocial status. Hence, it is recommended that the biopsychosocial approach be promoted in medical treatment through training and interventions for medical staff, primarily geared to those with the lowest probability of actively focusing on the patients' psychosocial status. Further, it is suggested to comprehensively popularize the knowledge of medical psychology among medical staff and carry out the research of disease psychology, which will help strengthen the medical staff's attention to the biopsychosocial medical model. Then, in medical practice, guidelines for implementing the biopsychosocial medical model should be formulated so that the patients' disease's biological, psychological, and social components are considered and managed as a whole. For example, medical and psychology departments could establish an efficient consultation, referral, or a multi-disciplinary treatment team to enhance patient diagnosis and treatment.

## Strengths and Limitations

This research explored the integration of the biopsychosocial approach into health care from the perspective of medical staff and patients. Using qualitative and quantitative methods, the study provides comprehensive information and fills a gap in the research on the application of the biopsychosocial approach. The study included a diverse and extensive sample of medical staff, as well as interviewing doctors and patients for their perspective on the issue. Furthermore, the study investigated sociodemographic variables in relation to

medical staff's attention to patients' psychosocial status. As such, the study provides scientific evidence for carrying out effective interventions to promote the implementation of the biopsychosocial approach in healthcare.

This study has some limitations. Firstly, although the sample included 13,105 medical staff in Hangzhou City, the results may not be generalizable to the situation of medical staff in other countries and regions. Future research should focus on other countries and regions with comparative analyses. Secondly, Study 2 used self-report questionnaires, which are subject to response bias such as social desirability. Lastly, this is a cross-sectional study which does not show how these variables behave over time. Future studies should consider using longitudinal designs.

## CONCLUSION

Although the biopsychosocial approach has been popularized for many years, it has not been widely used in medical care. The results of the present study suggest that medical staff tend to focus their attention on the patients' physical symptoms and are less inclined to attend to patients' psychosocial status. Gender, department, hospital level, professional title and the interaction of age and years of employment can play a predictive role in the extent to which medical staff pay attention to patients' psychosocial status. Therefore, it is recommended that training and interventions be provided for medical staff on integrating the biopsychosocial approach into the provision of health care. In developing and implementing any in-service training for medical staff, it would be important to consider how the factors identified in this study may impact the ability and motivation of medical staff to attend to the psychosocial status of patients. Additionally, we propose guidelines be formulated for implementing the biopsychosocial approach, and helping patients set reasonable expectations regarding what the medical staff is able to do given

their job responsibilities and the timeframe they have to provide diagnosis and treatment.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by ethical review institutions of Zhejiang University and related hospitals. The participants provided their informed consent to participate in this study.

## AUTHOR CONTRIBUTIONS

QY, XX, and HS contributed to the conception of the study. HS, TS, and ZW collected the data. YX and XX carried out data cleaning. XX performed the data analyses and wrote the manuscript. QY and HS contributed to critically revising the manuscript for important content. All authors have read and agreed to the published version of the manuscript and contributed to the article and approved the submitted version.

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# Reimagining Community Mental Health Care Services: Case Study of a Need Based Biopsychosocial Response Initiated During Pandemic

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Community mental health systems worldwide have undergone transformation in order to accommodate enormous demands of the pandemic and its mitigation efforts. The pandemic created unprecedented challenges that required Mehac Foundation (further referred as Mehac), a not for profit organization based in Kerala, to reassess our care delivery model. The aim of this report is to present a flexible, need-based biopsychosocial response; a case study effectuated by the Non-Governmental Organization (NGO) with a focus on minimizing the impact of COVID 19 on vulnerable communities, while adhering to timely regulations issued by the government. The key aspect of our biopsychosocial response was implementation of a phased approach that was rooted in real time need identification. The strategies will be described under broad headings of (i) adaptations for maintaining continuity of care, (ii) identifying vulnerable subgroups and need based psychological response, (iii) exploring social dimensions of the pandemic and implementing strategies to address them, (iv) ensuring team well-being and enhancing skills to effectively respond to the challenges.

**Keywords:** COVID 19 pandemic, community mental health, psychosocial support strategies, role of NGO, Mehac foundation, community based organization

## INTRODUCTION

COVID 19 pandemic has disrupted the functioning of mental healthcare worldwide and has presented a dreadful challenge to community mental health care (1). It has without doubt resulted in an instant escalation of mental health issues globally. At the beginning of the pandemic, there were predictions about India's inability to cope "India has a high risk of community transmission because of crowded living conditions, congested cities, a large slum dwelling population, poor health-care facilities, low educational attainment, and high levels of poverty" (2). In addition, there have been concerns about mental health and psycho-social consequences of self-isolation and sudden lockdown, which has affected usual life and routines of people and in turn has led to an increase in loneliness, anxiety, depression, insomnia, substance use, self-harm, or suicidal behavior (3, 4). The psychosocial impact of the pandemic still remains mostly unresolved and unaddressed; a recent survey by the Indian Psychiatric Society shows that 2/5th of the people surveyed were experiencing common mental health disorders since the coronavirus outbreak (3). Managing the direct and

secondary effects of the pandemic and also implementing the solutions are difficult for developing countries like India, with an approximate population of over 1.35 billion people.

As per the National Mental health Survey (NMHS-2016), nearly 150 million Indians (urban > rural) are in need of active mental health interventions, but the treatment gap for overall mental morbidity was 84.5% (5). Though Kerala fares better in terms of number of personnel and health facilities, it has a higher suicide rate of 24.3 when compared to national average of 10.4. India has a three-tiered health-care system for delivering preventive and curative services along with private health care facilities (6). District mental health programme forms the fulcrum of service delivery by the government for mental illness at primary care level however, there are bottlenecks at various levels from policy to implementation and utilization (7). Hence, to bridge the existing treatment gap and address inherent disparities in the system, scaling up of services with alternatives like Non-Governmental Organization (NGO)'s are invaluable in Indian setting. This scenario was made more evident during the ongoing pandemic where maintaining services at grassroot levels were further strained.

## MENTAL HEALTH CARE AND RESEARCH FOUNDATION MODEL

Mental Health Care and Research Foundation (Mehac) Foundation, is a not for profit organization working in the southern part of Kerala, India, since the year 2008. Pain and palliative care (PPC) movement (8) in Kerala laid the foundation for Mehac to eventually adapt palliative care principles to mental health care. The mission of the foundation is to evolve and propagate a new model of mental health care, by strengthening existing systems in the community and thereby increasing community participation. Mehac executes a flexible model of community psychiatric care through its partnership with community-based organizations (CBO) based on Public-Private-People Partnership (4P's). Collaborative arrangements with Panchayats (local self-government department), private sector, and civil society help Mehac to sustain programmes in the community and cater to the marginalized sections of the society. Over the past 12 years, the foundation has touched the lives of more than 5,000 people with mental health issues in six districts of Kerala delivered by a multidisciplinary team.

Mehac emphasizes cost effective quality care; it had humble beginnings with donations from likeminded philanthropists. Currently the services are supported by governmental organizations like Panchayats, partnering civil society organizations and individual donors. Corporate organizations have come forward with their social responsibility grants as well.

Mehac's volunteer system was developed based on the Neighborhood Network in Palliative Care initiative (NNPC) which is an exemplar model for resource poor settings (9). A volunteer in the community would be someone willing to contribute specific time for the care of people, who undergoes training and is willing to be supervised, and works with a team. Most of them would have passed their high school education.

They vary from lay volunteers to community level health workers like Accredited Social Health Activist (ASHA) (10). They are trained and empowered to address stigma and facilitate early identification and intervention through referral pathways. These volunteers are identified by local CBOs from within their communities and they act as a bridge between the expert team and community. In a collectivistic society like India, the family of a Person with Mental Illness (PwMI) plays a major role in caregiving (11). Mehac considers Family as the unit of care and ensures their maximal empowerment to increase participation in management of our patients. Engaging through volunteers and families has ensured high rates of compliance and prompt identification of relapses.

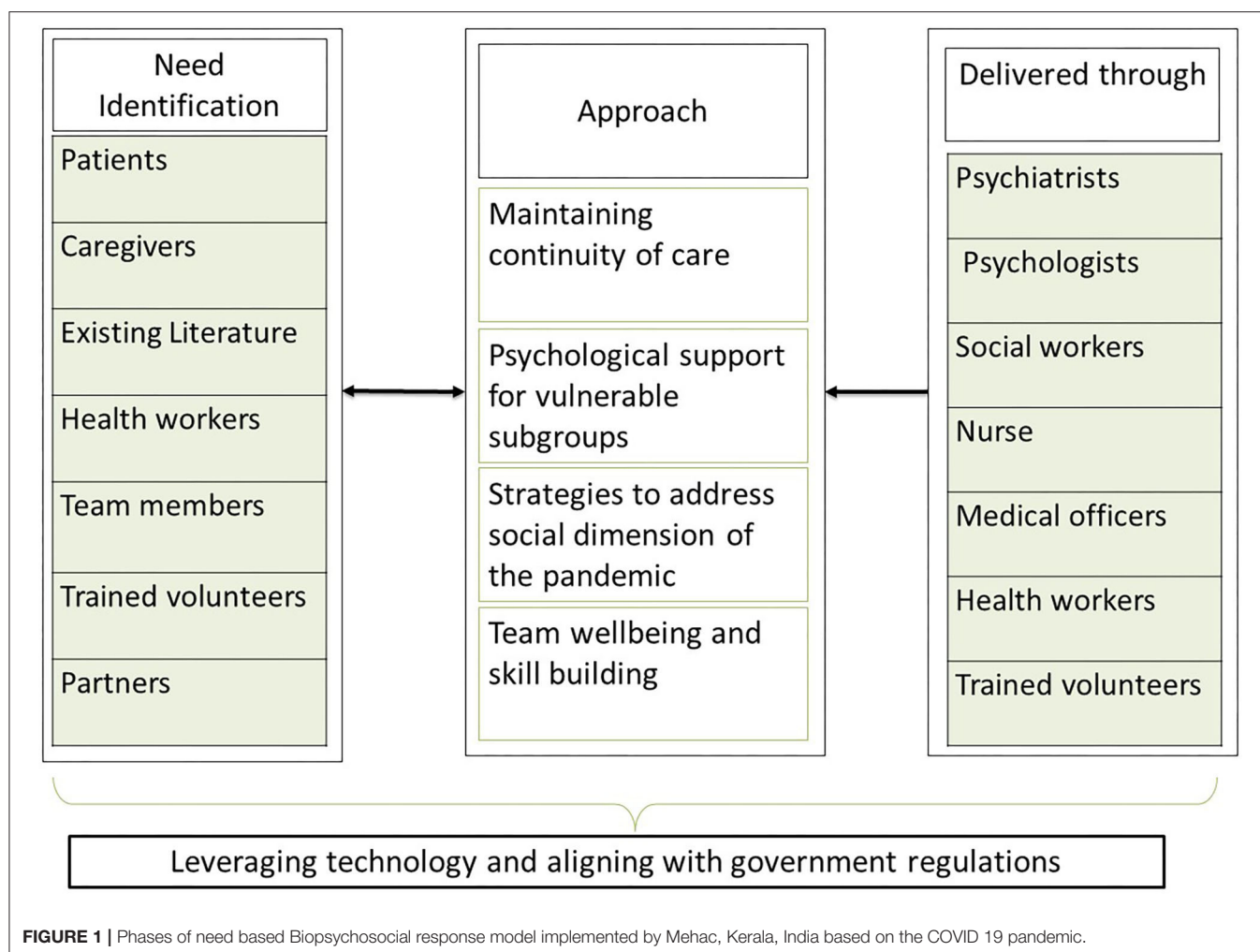
Mehac functions by empowering CBOs to take ownership by providing an expert consultancy role and a stepped care approach enabling delivery of medical, psychological, and rehabilitation services. Access to free medicines and necessary infrastructure support are ensured by the partners. We run a total of 22 clinics, 68% of which function in collaboration with the local NGOs and 32% in partnership with Panchayats. Prior to the pandemic, consultations were done for 2,852 patients through clinics (88%) or home visits (12%) requiring travel (on an average about 50–60 km per day). Medications were also dispensed either directly at clinics (92%) or through home visits (8%).

## NATIONAL AND STATE RESPONSE TO PANDEMIC

India's first COVID patient was reported from Kerala in January 2020, which was contained with active measures (4). However, by February 3<sup>rd</sup> Kerala, had declared a state calamity and by March 11<sup>th</sup> WHO, had declared it a pandemic. The situation worsened and by March 22<sup>nd</sup> "Janata Curfew" a one day voluntary lockdown was announced. On March 24<sup>th</sup> Kerala declared a statewide lockdown, followed by Indian Government imposing a nationwide lockdown on 25<sup>th</sup> March. India's lockdown was extended till May 31<sup>st</sup>, it was one of the strictest and longest in the world (4). The nationwide lockdown was carried out in four phases; the initial two phases were very strict with restricted movements across the country, and the latter two phases saw gradual and contextual relaxations based on case load with clearly defined containment zones. By June 8<sup>th</sup>, phased reopening was announced. The lockdown, inspite of its perceived success, also drew wide attention because of its negative socioeconomic impact (12). Kerala government, by pooling existing facilities in the government, private and voluntary sector was able to implement innovative strategies, effectively cutting down the spread of COVID 19, and minimizing its psychosocial impact during early days of the pandemic (13, 14).

## BIOPSYCHOSOCIAL RESPONSE MODEL IMPLEMENTED BY MEHAC

The overall functioning of our CBOs were adversely affected by the sudden lockdown. In response, we adopted a multipronged-multidisciplinary biopsychosocial approach (15) (see **Figure 1**),



which was based on evidence from existing literature and real time need identification through continuous feedback from patients, their families, community volunteers, community health workers, community partners, and the team members. More than 90% of our beneficiaries belong to the lower socioeconomic status (16) with limited access to mental health services, hence providing consistent treatment services to them was crucial. This was achieved by restructuring our service delivery with adaptations to existing biopsychosocial approaches and effectively leveraging available and affordable technology options. The strategies were devised giving careful attention to the social, cultural, and economic background of the beneficiaries as well as the updated regulations by the Government.

The key aspect of our Biopsychosocial response was time sensitive adaptation to the needs arising in the community. The strategies were implemented in a phased manner: (i) initiation-phase from the time the pandemic was declared a state calamity to the first two phases of strict lockdown (ii) the transition-phase from third phase of Lockdown to stepped reopening and (iii) the continuation-phase from reopening to new normal functioning.

We adopted a need based phased response not only to follow governmental guidelines but also to be prepared for

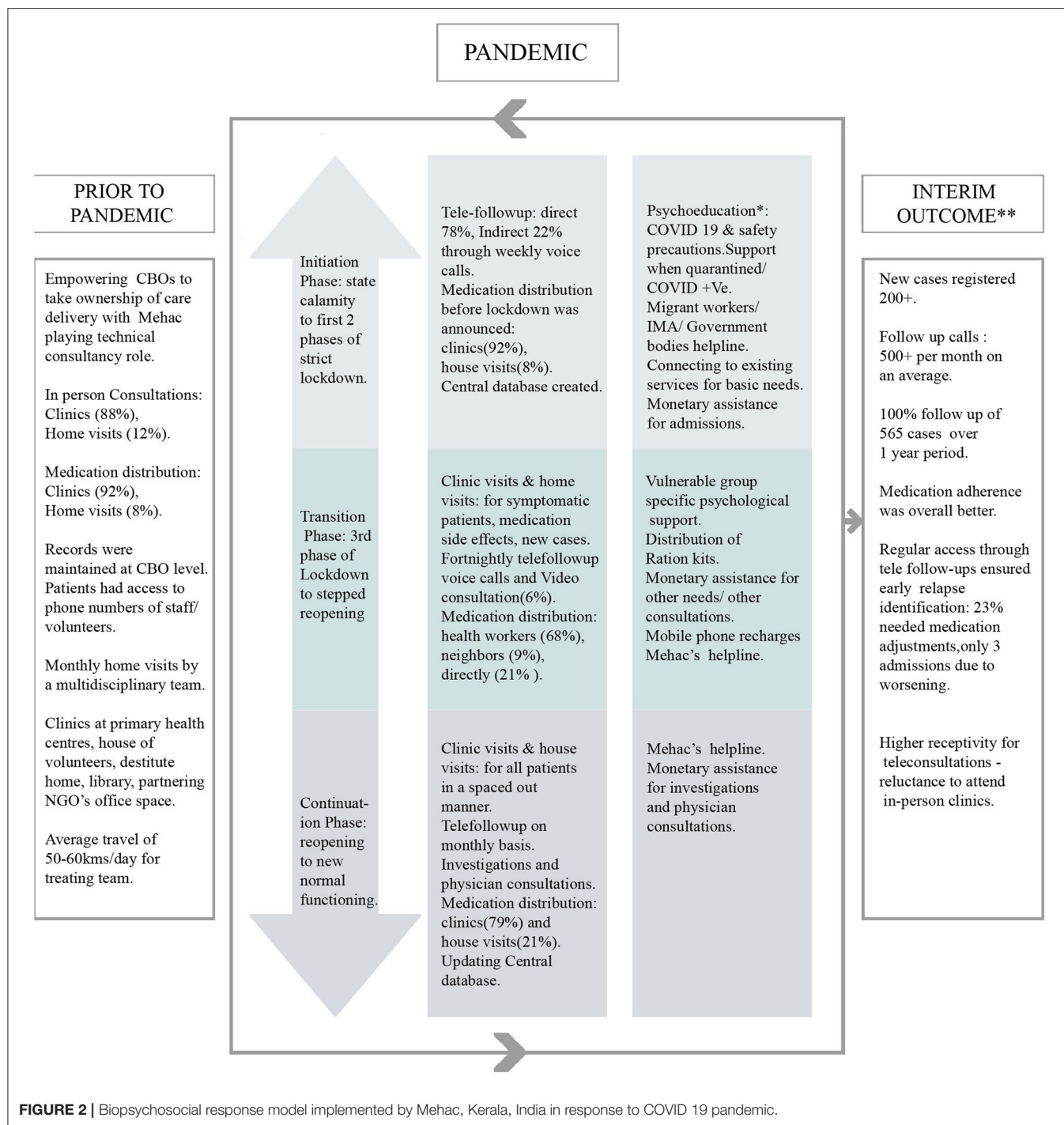
future resurgence (17). The strategies described in a phased manner are flexible and cyclical and not linear (see **Figure 2**). It will be described under broad headings of (a) adaptations for maintaining continuity of care, (b) identifying vulnerable subgroups and need based psychological response, (c) exploring social dimensions of the pandemic and implementing strategies to address them, and (d) ensuring team well-being and enhancing skills to effectively respond to the challenges.

## ADAPTATIONS FOR MAINTAINING CONTINUITY OF CARE

COVID 19 made restructuring of our services mandatory. Around 95% of our patients suffer from severe mental disorders and hence maintaining continuity of care during the pandemic was crucial. Out of a total number of 2,852 patients in our service, 565 had regular direct followup (teleconsultations/visits), for rest of the stable patients from referrals and outreach centers, more than 500 needs-based help was extended.

During the initiation phase, the team tried to maintain regular follow-up with patients and their families either directly





(78%) or indirectly (22%) through volunteers, health workers, or neighbors. Follow up calls were done mainly through voice calls as that was the easily available option to overcome existing digital divide (18). Initial follow-ups were done on a weekly basis, wherein enquiry was made regarding current status of patient, their biological and socio occupational functioning as well as medication adherence. As there were predictions of increased chances of relapse or worsening in patients with pre-existing

mental health issues as was being reported from the world over (19–21), these strategies helped in identifying early signs of relapse. In the initiation phase, patients were followed on a weekly basis and then it was eased to fortnightly during the transition phase as most of the patients were stable. In the transition phase, we conducted a survey to understand if patients preferred returning to in-person clinics. Sixty-three percent wanted to visit clinics whereas 37% preferred home care visits.

*“COVID cases are increasing here, all of you stay at home. R (volunteer with Mehac) ensures that medicines reach us on time you call and ask about me and my daughter, do not come to hospital to see us now. Ask everybody else in the team to stay safe, we will call promptly if we have any other problems.”*

- Mother of a 20 year old PwMI

Mehac followed a hybrid model further into the transition phase; incorporating home visits, in-person clinics, and regular tele follow ups. Initially patients who needed in-person consultation were seen selectively. An arbitrary criteria was applied and those who were symptomatic with medications changes being indicated, or those who were experiencing any side effects of medications were seen in nearby clinics with well-spaced out appointments to ensure social distancing and to avoid overcrowding. Each of the appointments were fixed with reiteration of safety precautions, as patients with severe mental illness were predicted to have difficulty following the same in view of impaired insight and decision making capacity (14). Strategies were constantly revised and we shifted toward virtual clinics wherein the social workers or psychologists would follow up with the patient along with a psychiatrist. Video consultations were arranged for 6% of patients, with help of younger family members or neighbors. As the situation eased, we encouraged patients and their family members to come to clinics along with continuation of tele follow up during the interval between clinic visits. In-person consultations were arranged only when need arose for the same. After the lockdown was lifted, tele follow ups continued with adjusted timings, as many of our patients and family members became unavailable during working hours.

All emergency consultations were either seen in-person or through virtual means. Existing ties with governmental and other volunteering agencies enabled Mehac to access local health care professionals and ensure timely help, thereby minimizing need for admissions. Medicine dosage was altered for those patients who couldn't be given long acting depot injections and they were monitored closely for early signs of relapse. Patients on clozapine were also closely monitored for any side effects and relapse of symptoms.

Mehac tried to address the issues of patients with comorbidities since patients with severe mental illness generally have higher rates of comorbidities and are vulnerable due to substantial disparities in access to health care (22). COVID 19 further compounded this vulnerability. Around 96 persons were identified with co morbid conditions like diabetes, hypertension, parkinsons disease, dementia, epilepsy, stroke, paraplegia cardiovascular disorders, chronic respiratory illnesses, chronic renal failure, etc. Home visits and video consultations were conducted exclusively for them in order to minimize risk of contagion. For similar concerns, family members with comorbidities, especially those that were elderly and were the sole caregiver for patients were also discouraged from visiting in-person clinics. In a survey conducted, we found people with comorbid conditions were hesitant to access health care services and mean duration from last physician visit was 6 months. Mehac utilized its ties with government and local volunteering organizations to link such patients to existing services for investigations and consultation.

*“This is the first time in my life that I have not been able to find a job for such a long duration, it's all because of the pandemic. Government ration kits and the free medicines you provide are keeping my family from starving. My wife has illness since 20 years, before a lot of my earning was spent on medicines and hospital bills as she had relapses when I could not afford medicines. I can't imagine how we would have got through these tough times without these medicines reaching us so promptly.”*

- Husband of a 50 year old PwMI

Challenges in maintaining a medication supply was reported worldwide (1, 23). Continuing the same without any disruption in the absence of our established outpatient set up was another major obstacle that we faced from the early days of pandemic. To ensure adequate supply through the period of lockdown, we communicated in advance with more than 90% of our patients to collect medicines. Adequate stock of medications was ensured by coordinating with various stakeholders, ranging from medicine suppliers to local partners and volunteers. Mehac raised funds and supplemented purchase of medications when the shortage was due to administrative/financial reasons. We created various subzones within the zones of our existing clinic areas and when patients were not able to travel to clinics, we coordinated with community volunteers, health workers, or neighbors to ensure seamless distribution of medications. When needed, field supervisors stepped up to make arrangements and ensured inter organizational cooperation between local partners. Timely improvisations were made to our existing model with 68% of medicines being distributed through help of health workers, 9% through neighbors, and 23% being collected directly from clinics. Even when lockdown was eased and eventually lifted, we continued a similar mode of delivery of medications in coordination with various stakeholders demonstrating long term learning. Overall these adaptations ensure 100% follow up of our patients with improved compliance to medications.

## IDENTIFYING VULNERABLE SUBGROUPS AND PSYCHOLOGICAL RESPONSE

When it comes to COVID 19, certain groups were found to be more vulnerable psychologically. Among them were persons with severe mental illness, elderly people, children (especially those with mental health issues) and migrant workers (24–30). Kerala's response in providing psychosocial support for these groups has received worldwide recognition. Telemedicine portal e-sanjeevani for teleconsultation across the State and “Ottakalla oppamundu” (You are not alone, We are with you) for providing psychosocial support were a few of the models recognized by the WHO. The government adopted an inclusive approach and addressed the special needs of vulnerable population (13, 14, 31).

*“I can't talk to anybody about my worries, my daughter doesn't support me and she has no time to listen to my problems even if I call her. I am not able to go out like before and nobody visits me now. You call and enquire about me regularly; you are more like a family to me now. Though you can't come, you made sure that help reached me through ASHA worker. Knowing that I can call you gives me hope.”*

- 69 Year old PWMI, living alone

Incorporating these principles, Mehac partnered with government bodies and other local NGOs to provide psychosocial support to vulnerable populations. In partnership with the government bodies, Mehac was involved in providing teleconsultation services to migrant workers and COVID positive patients. Additionally, partnering with IMA's (Indian Medical Association) telemedicine services, Mehac extended support for people who were COVID positive and in quarantine. Apart from this, for its existing patients Mehac provided weekly teleconsultation services especially to people with severe mental illness and their caretakers, elderly, children with mental health issues, people living alone, those with co morbidities and those who tested positive for COVID. In the initial phase, we provided psychoeducation regarding COVID symptoms, precautionary measures and its impact. Throughout the period of lockdown special attention was also given to families of PwMI and their distress was addressed. In our experience, families were resilient and their concerns were more related to meeting financial needs. Though there were media reports of increased violence during lock down, among our population we encountered one such incident and were able to liaise for help with the established governmental women helpline. Psychological first aid principles were applied in practice when indicated to allay fears. Supportive psychotherapy was also provided on an individual basis when needed. Both physical and mental health issues of these groups were addressed by partnering with available resource people within the community.

## EXPLORING SOCIAL DIMENSIONS OF THE PANDEMIC AND IMPLEMENTING STRATEGIES TO ADDRESS THEM

*"My husband and me have not been able to find any jobs as nobody is hiring daily wage workers now. We were able to manage somehow though the Government ration kits, but the debts in the grocery shop were piling up and we couldn't buy vegetables or meat for our children. With the money you gave me instead of the ration kit, I could pay my debts at the shop and buy fish for my children after a long time. I can't explain how happy my children were."*

- Wife of 56 Year old PwMI

COVID 19 has brought a complete breakdown of social support systems across the world. In addition, people with existing mental, neurological and substance use disorders constitute an already economically vulnerable group who are susceptible to chronic poverty and relapse (31). The Kerala government initiated timely measures such as ensuring food kits to all, supplying mid-day meals to children at home, ensuring free meals for migrant workers etc., to mitigate psychosocial impact of the pandemic (32, 33). During the initiation phase, follow-up by the team revealed that most of the ground level apprehensions were related to interruption in the supply of basic material needs due to the lockdown. This was addressed by connecting them to various services offered by the government, voluntary organizations, or other NGOs. After lockdown was lifted, the government continued supplying ration kits and other basic necessities, but people lacking ration cards or those wrongly

categorized as Above Poverty Line (APL) (34, 35) had difficulty in availing these services. Hence, Mehac stepped up and identified such people in each clinic and started distributing ration kits ( $n = 31$ ) and other provisions as needed. Even though the majority of people had access to food through various schemes, many of them were seen struggling to meet other basic needs as they didn't have sufficient money at hand due to job loss and unemployment. Monetary assistance was provided for such people. Mehac also took care of consultation fee and transport assistance for those who warranted hospital visits for other physical issues or to facilitate admissions when symptomatic.

Research shows that maintaining social support has higher scores on recovery for people with severe mental illness (36). The pandemic along with its mitigation efforts have resulted in making telecommunication services a basic necessity. Hence, maintaining regular connectivity with our beneficiaries and helping them to connect with their dear ones was vital in order to keep them calm and informed. Identifying this need, Mehac made efforts to recharge mobile phones of beneficiaries when needed. Realizing the magnitude of crisis on the ground Mehac conducted timely fundraising through individual donors and corporations who were willing to support through their social responsibility grants.

## ENSURING TEAM WELL-BEING AND ENHANCING SKILLS TO EFFECTIVELY RESPOND TO THE CHALLENGES

*"How was I going to understand people emotions through a voice call? I rely so much on talking face to face to do my work in the community. I was apprehensive about this however, discussions with my team mates and exercises like role plays gave me the initial confidence. My patients and their family helped me gain more insights through the sessions over phone. After initial few calls I realized that, though my barriers increased in reaching out to them in person, they could reach out to me better, which in turn meant very few of my patients had any major problems."*

- Social worker with Mehac

Healthcare workers are considered a vulnerable group due to high risk of infection, increased work stress, and fear of spreading the infection to their families (37, 38). In order to cope with challenges that the pandemic posed, it was crucial to strengthen team dynamics and foster cooperation. Peer group surveys identified stress of the ongoing pandemic and guilt of spreading infection to family members prevalent among team members. The remote mode of operating necessitated work from home which resulted in team members facing problems within their personal sphere as well. However, the existing dynamics and rapport within team members ensured a sense of solidarity that in turn helped to ease apprehension and worries. Strategic adaptations were made through frequent communications and feedback. The team made an effort to identify and gather accurate information about safety precautions and government rules and regulations regarding the pandemic. The information gathered was passed on to the beneficiaries through teleconsultation which helped in dispelling anxiety created by misinformation.

The whole process of acquiring and disseminating accurate information helped to reduce the team's anxiety as well.

Regular discussions helped troubleshoot problems and refine strategies. Different communication channels were established and various contextual groups were created to develop strategies and to attend to emergencies. Even though there were frequent connectivity issues, the team experimented with various online platforms such as Zoom, Google Meet, etc., to identify a platform that was comfortable for all. When gaps in patient follow up were identified, the team shifted to password protected excel spreadsheets for ease of follow up and communication. Enhancing skills like planning and communication was identified as a felt need among the team members. Various training sessions with specific modules, empowerment, and review sessions were conducted. The team actively participated in online webinars to update knowledge regarding COVID 19 and its impact as well as psychosocial strategies to address it. Team members were part of developing a "Resource Toolkit for Low and Middle Income Countries for Palliative Care in COVID 19" (39) which was also extended as an online training program.

## CONCLUSION

The Mehac model of task sharing (40) and community participation provided the advantage of a strong ground support system that helped in an expeditious transition to a remote mode of operating. The readaptations made by leveraging technology enabled us to strengthen our care delivery model further; ensuring overall better follow up with improved compliance to medication when compared to previous year. A phased approach rooted in real time identification of perceived needs and barriers enabled us to not only sustain continuity of care but also to focus on social needs. These strategies in turn helped in building a sense of community support and seem to enhanced resilience in our vulnerable population (41). Constant evolution of the model based on government regulations and identified needs helped in designing localized solutions with maximal use of available community resources, thereby encouraging our beneficiaries to exercise agency. Responsive leadership and open channels of communication within the team helped in achieving better patient care and ensuring team well-being.

The abruptness and evolving nature of the pandemic resulted in initial difficulty in devising systems for tracking data, hence the results mentioned here are interim, impressionistic, and

clinically based. Limitations include not gathering quantitative and experiential data to measure outcomes; there was no formal evaluation during the pandemic. Technology was not leveraged enough to conduct support groups, caregiver sessions for families, or awareness programs which were conducted on a regular basis prior to the pandemic. For future pandemics or other community crisis, ideally we will be prepared to assess the outcomes of this model implemented during the COVID 19 pandemic using mixed methods with quantitative tools and surveys to measure outcomes as well as qualitative evaluation to study the process indicators like satisfaction, readiness, challenges, and barriers along with acceptability, appropriateness, adoption, and feasibility of interventions through key informant interviews and focus groups. Replication requires testing adaptations in different societal structures. Generating discussions around political will and societal attitudes are crucial to designing culture- and context-specific interventions as well as pathways for funding.

The inherent ability to adapt to changes, while respecting individual autonomy and empowered participation of various stakeholders are crucial for a sustainable community model. Sensible local application of broader concepts of cost effective biopsychosocial approaches mentioned here can ensure accessibility of care for even the most underserved sections of the society in a resource limited setting. Sharing experiences and evaluations, negotiation with policy makers are important components to replicate resilient community led approaches in other settings.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## AUTHOR CONTRIBUTIONS

PS and AV were major contributors to conception, designing, and writing up the manuscript. MS, AM, GP, and AP carried out surveys, helped in updating database, and wrote sections of the manuscript. RR helped with interpreting database and carried out proof reading. MA, AR, and CV gave valuable inputs to improve the overall outlook. All authors contributed to manuscript revision, read, and approved the submitted version.

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# Commentary: Reimagining Community Mental Health Care Services: Case Study of a Need Based Biopsychosocial Response Initiated During Pandemic

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## A Commentary on

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As a professor at a Western medical center, I first want to acknowledge my inexperience with the Indian healthcare system as well as resource differences that exist between our care systems. Also, I work at the University of Rochester Medical Center (URMC), which gave birth to the biopsychosocial model and is the focus of this special issue. With these standpoints in mind, I offer the following commentary on Sunder's et al. recent article (1). I'll begin with some background about URMC followed by discussion of the coronavirus pandemic to provide context. Then I will discuss the exemplary work currently being done in Kerala, India along with our local efforts to address the pandemic. Lastly, I'll highlight potential advantages of Kerala's innovative approach to care.

## THE BIOPSYCHOSOCIAL MODEL

The biopsychosocial model was proposed in 1977 by Engel (2) who trained as an internist, in collaboration with psychiatrist Dr. John Romano (3). In contrast to the prevailing biomedical ethos of the time and its myopic focus on biological processes, Engle and Romano's theory provided conceptual links between the body, the mind, and society. Yet translating this conceptual framework into clinical practice has remained a challenge for mental health service delivery in the United States. A 2009 report by the National Alliance on Mental Illness (NAMI) rating overall quality of mental health services gave the United States a "D" grade (i.e., unacceptably poor) (4). One of NAMI's key recommendations was to better integrate mental and physical healthcare through co-location of medical and behavioral health professionals. Progress has since been made in service integration (5, 6), forging real-world healthcare bridges between the biological and psychological dimensions of the biopsychosocial model. The coronavirus pandemic, however, has recently revealed an alarming disconnect between healthcare and society in the United States.

## THE GREAT PANDEMIC

The coronavirus pandemic has now accounted for more deaths in the United States than the Influenza Pandemic of 1918 (7), this despite advances in public health and widely available vaccines. Many in the United States refuse to be vaccinated or to wear masks despite the proven effectiveness of these strategies (8–10). In explaining this impasse, scholars have pointed to the role of social and cultural factors including politicization and media sensationalism (11, 12). These influences have led some to view public health practices as an affront to personal liberty, thus undermining trust in medical authorities and healthcare providers alike.

People with severe mental illness are among those now bearing the brunt of the pandemic (13). For example, individuals with schizophrenia have high rates of mortality following coronavirus infection (14) in addition to having poor access to healthcare services (15, 16). Lockdown strategies to contain the virus have threatened to further limit healthcare access both here in Rochester and in Kerala, India. In response, healthcare providers in both regions have worked to promote access to treatment for people with severe mental illness through telehealth strategies. Yet there have also been differences in how these communities have faced the challenge of delivering healthcare to their most vulnerable citizens in the midst of a deadly pandemic.

## KERALA, INDIA

Prior to the pandemic, Kerala had developed a reputation for achieving good health outcomes despite having a low per capita income (17). With limited healthcare resources, Kerala's Mehac Foundation undertook a novel and highly efficient approach to care delivery that required broad and active community participation. Borrowing from the field of palliative care, the foundation implemented a flexible model of service delivery based on Public-Private-People Partnership (1). This approach utilized existing community resources including public governance organizations (e.g., panchayats), private organizations (e.g., non-governmental and corporate organizations), and—most notably—people (e.g., family members and volunteers). Getting all of these individuals and organizations to pull together required a shared sense of purpose as well as high levels of communication and cooperation. Mehac provided the necessary vision while using existing ties with governmental and volunteering agencies to access local healthcare professionals, to link patients to services and to ensure medication delivery. The foundation also made substantive efforts to supply education, food, and monetary support to those in need.

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## ROCHESTER, NEW YORK, USA

The URMC Department of Psychiatry is home to Strong Ties, an outpatient clinic for people with severe mental disorders. Prior to the pandemic, over 90% of services were delivered within the walls of our clinic. At the height of the pandemic, Strong Ties utilized telehealth services for 70% of all patient contacts. Live visits were generally limited to crisis intervention, new patients and those without telephone or computer access. Delivery of medications, clothing and food was conducted through a team of care managers and two assertive community treatment teams along with use of community pharmacies for prescriptions. Although these approaches ensured continuity of care, they did not necessarily build resilience among service recipients.

## COMMENTS FROM ROCHESTER TO KERALA

Mehac's novel strategy of involving a wide-ranging coalition of agencies and individuals is consistent with current recommendations for optimizing continuity of care for people with severe mental illness during the pandemic (18). However, Mehac's implementation is likely to have significant benefits beyond simply maintaining continuity of healthcare. In particular, their emphasis on community engagement may *improve* mental health by directly addressing social determinants including poverty and lack of health literacy (19, 20). Also, research has suggested that being negatively judged by others is among the most harmful stressors for people with severe mental illness (21). Such stress within family settings is strongly associated with increased rates of psychotic relapse and hospitalization (22). Mehac's efforts to educate, support and empower "family as the unit of care" are therefore likely to reduce the need for psychiatric hospitalization by reducing stress and stigma within the home. Lastly, engaging a broad social fabric of community stakeholders is likely to build confidence and trust in healthcare professionals as leaders in the fight against COVID-19.

Sunder et al. (1) have acknowledged that a formal evaluation of Mehac's approach has yet to be conducted, and we look forward to that possibility. Until then, I commend my Indian colleagues for their exemplary leadership in addressing the social dimension of the biopsychosocial model.

## AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

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# A Biopsychosocial and Interprofessional Approach to the Treatment of Family and Intimate Partner Violence: It Takes a Village

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Family and intimate partner violence and abuse (FIPV) is a critical public health problem with repercussions for mental and physical health. FIPV exposure also is associated with social difficulties such as low socioeconomic status, legal issues, poor access to employment and education, housing instability, and difficulty meeting other basic needs. As a biopsychosocial problem, one discipline alone cannot adequately address FIPV. While individuals who experience FIPV traditionally seek respite, care and safety through domestic violence shelters, social services or courts, they also often present to health care settings. Building on the medical-legal partnership model with critical input from a community advisory board of individuals with lived experiences of FIPV, we implemented a person-centered approach in the health care context to cohesively integrate legal, safety, social, psychological and physical health needs and concerns. The purpose of this paper is to describe the Healing through Health, Education, Advocacy and Law (HEAL) Collaborative for individuals who have experienced psychological abuse, physical abuse, sexual abuse, or neglect related to child maltreatment, intimate partner violence, and/or elder abuse, and review our real-world challenges and successes. We describe our interprofessional team collaboration and our pragmatic biopsychosocial framework for bringing together: professional and stakeholder perspectives; psychological, medical, legal, and personal perspectives; and clinical, evidence-based, and educational perspectives. There is no doubt that creating a program with biopsychosocial components like HEAL requires professionals appreciating each other's contributions and the need to begin working from a common goal. Furthermore, such a program could not be successful without the contributions of individuals with the lived experience we seek to treat, coupled with the external health care clinicians' input. We describe lessons learned to date in an effort to ease the burden for those seeking to implement such a program. Lessons include HEAL's more recent clinical adaptations to serve patients both in-person and via telehealth in the wake of COVID-19.

**Keywords:** biopsychosocial, interprofessional teams, medical-legal partnership, stakeholder engagement, family and intimate partner violence and abuse

## INTRODUCTION

Individuals experiencing family and intimate partner violence (FIPV), defined as child maltreatment, intimate partner violence, and elder abuse (1), frequently interact with the health care system for needs both directly and indirectly related to their abuse (2–4). More specifically, FIPV poses risk for worsening physical and mental health conditions, including posttraumatic stress disorder, compromised sleep, headaches, gastrointestinal disorders, birth outcomes, and myriad mental health issues (5–7). FIPV also is associated with increased risk for complex social needs, such as food, unstable housing, homelessness, legal difficulties, and unstable employment (8–10), all factors that affect not only individuals' mental and physical health but access to health care.

Unfortunately, health care professionals often do not address FIPV because they miss it, report limited knowledge, or experience a lack of options when patients provide a positive endorsement (11, 12). Most outpatient visits by patients experiencing FIPV are for non-injury-related concerns. Health care clinicians often do not ask about victimization (13, 14), while many patients do not disclose FIPV without specific inquiry (15). Reasons why patients may not share their FIPV experiences with their health care clinicians include believing it is irrelevant, disclosing it is embarrassing, or past negative experiences when sharing it with other health professionals (e.g., being told to leave their partner when that was not what they wanted). Trauma-related symptoms, such as avoidance, distrust for others, hopelessness, and emotion dysregulation, may impact patients' experiences receiving care, and consequently their care may be re-traumatizing. Examples include invasive physical exams that trigger memories of sexual assault or being evaluated for FIPV in the presence of the person who abused them, which may result in the perpetuation of abuse or cause the individual to cease seeking care altogether (16).

The US Preventive Services Task Force has recommended FIPV screening for women of childbearing ages. Other professional health associations also recommend screening for FIPV within pediatric practices, mental health, primary care and women's health settings (3, 17). Screening can increase recognition of FIPV within health care settings. For screening to be useful, however, health care clinicians need training, support, resources and services for responding to positive screens (18). When FIPV is disclosed, generally health care clinicians are unprepared to help due to limited training, insufficient time with patients, and few resources readily available (19–22). Complicating matters, as already described, patients with FIPV can present with multiple, complex health conditions. Shifting from one specialist to another, they are offered multiple interventions, while none address the FIPV that may continue to exacerbate their symptoms.

A comprehensive, biopsychosocial approach to FIPV, by definition, should incorporate health, safety and social needs and be based on the patient's priorities (23). While offering resources can inform patients about critical services available to help with FIPV, a piecemeal approach can become overwhelming, confusing and unsafe for individuals facing multiple and complex difficulties. As a consequence, patients often experience barriers

to treatment engagement and health care clinicians often feel overwhelmed trying to coordinate care.

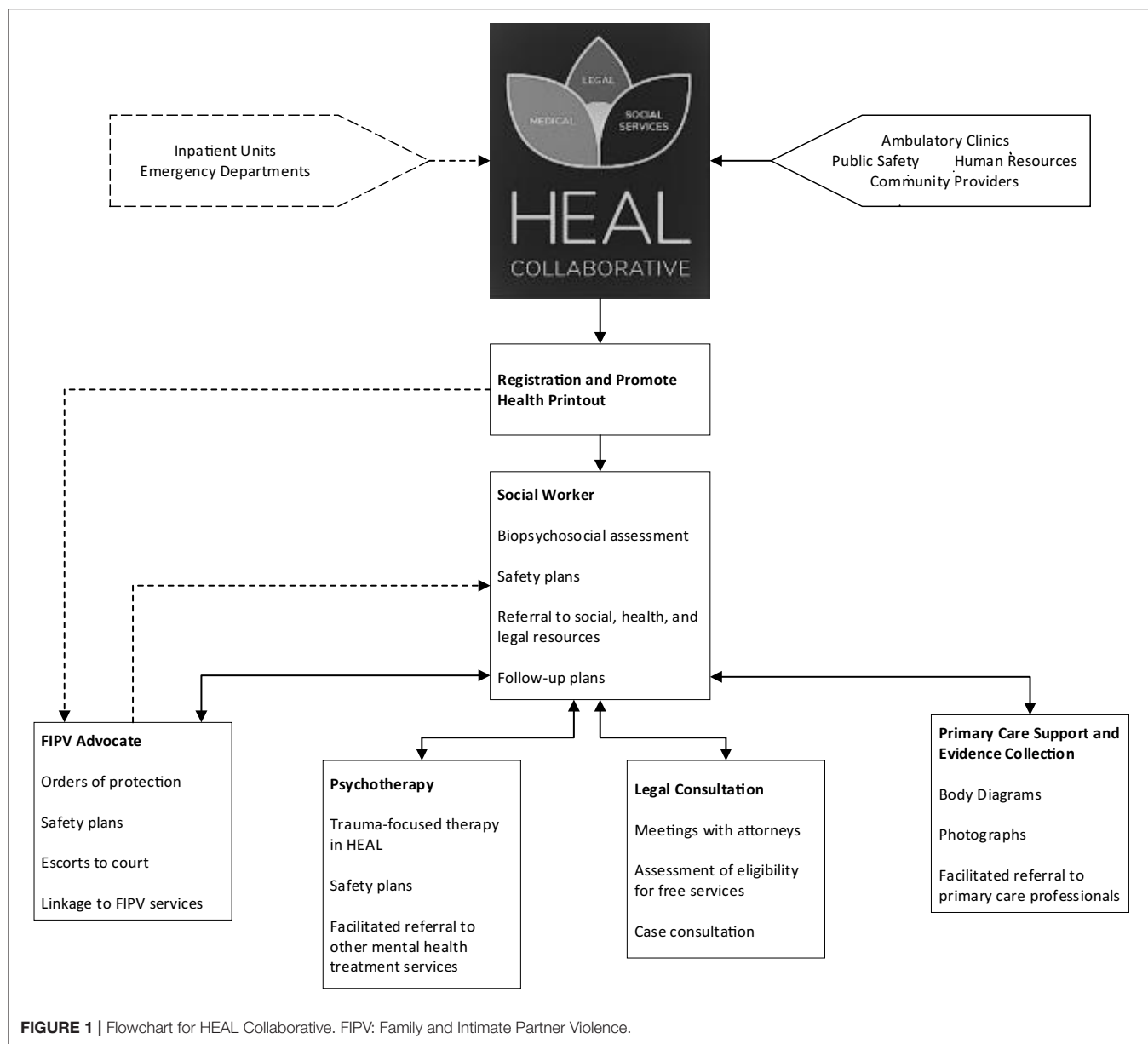
Community advocates with lived experience of FIPV approached an academic health center for help improving care, citing lack of sensitivity and fragmentation as significant barriers. They described wanting a collaborative and team-based approach within the health care context to help address their diverse needs related to FIPV. Limited evidence exists about how best to support individuals experiencing FIPV within health care. However, legal interventions can improve health. For example, when survivors sought safety via orders of protection (OP), some experienced less violence and health outcomes improvements (24, 25). A judge can issue an OP to prevent perpetrators of FIPV from contacting the individuals they abused. The judge determines that the violence surpasses a legal threshold, making behavior "illegal" under the law. Nationally, all states offer OPs through criminal or civil court, or both. Often individuals experiencing FIPV receive their health and legal care siloed, yet more than half seeking OPs for FIPV at one court reported mental health symptoms needing assessment (26).

## CONTEXT

We established the Healing through Health, Education, Advocacy and Law (HEAL) Collaborative as a partnership between an academic health center, a domestic violence center, a domestic violence court, and a local legal aid society. HEAL is located in the Department of Psychiatry at our academic health center in Rochester, NY, and based on a medical-legal partnership (MLP) model. MLPs incorporate attorneys, health care professionals, and community partners to offer health, legal, and social services all in one location (27, 28). Hundreds of MLPs exist in nearly all US states (29). MLP evaluations document they can reduce stress and improve the wellbeing of patients who utilize them (30–32). Moreover, academic health centers with MLPs reduce healthcare costs for vulnerable patients (27).

To date, MLPs primarily have consisted of legal consultants who hold clinics at primary care practices around concerns such as access to health insurance, disability applications, and eviction. We established HEAL as an MLP to offer coordinated legal assistance, social work support, trauma-focused psychotherapy, and medical consultation across the academic health center for FIPV, working in close partnership with outpatient primary and specialty care clinicians, the emergency department, and inpatient units, as well as community agencies (**Figure 1**). To our knowledge, HEAL is unique in three ways: (1) a focus on FIPV within the health care context; (2) the use of a discrete interprofessional team that provides support across different medical practices as well as both inpatient and outpatient settings; and (3) incorporation of stakeholder contributions as a key part of developing the program.

HEAL serves any adult in the Greater Rochester New York community coping with issues related to experiences of psychological abuse, physical abuse, sexual abuse, or neglect from child maltreatment, intimate partner violence, and/or elder abuse, with an emphasis on those served by our academic health



center. We serve patients without regard to race, ethnicity, gender identity, or sexual orientation. Youth are directed to our local children's program although we work with caregivers and families. Presenting concerns range from patients who are hospitalized due to injuries caused by their partner and wanting to prevent future contact to those beginning to explore abuse in their relationships to individuals who may be safe currently but have an unresolved history of abuse. The team has a secure suite of offices within an urban hospital and is mobile within the hospital to meet individuals in crisis in the emergency department or on inpatient units. HEAL staff follow-up with ambulatory care after discharge. The HEAL consultation service ranges from urgent calls when a professional is fearful of allowing an individual to leave with a partner, caring for an individual not yet ready or able to come to HEAL, informational calls about

community resources, and legal issues consultation. Our team consists of individuals with complementary expertise and skills: psychology, law, medicine, and lived FIPV experience (Table 1). This interprofessional team-based model supports a new system of care that integrates the many different needs of those who have experienced FIPV.

## Detail to Understand Key Programmatic Elements

The HEAL Collaborative is based on three practice foundations: (1). Creating an interprofessional team to collaborate closely to support the individual; (2). Utilizing evidencebased approaches, including using a MLP to address social needs that impact health in the context of a social determinants of health framework;

**TABLE 1 |** HEAL collaborative interprofessional team members.

Team members		Roles and contributions
Direct service	Social workers	Patient assessment, planning, support and resource connection; ensuring follow-up plan is implemented; collaboration and consultation with other professionals; IPV education
	Domestic violence advocates	Patient safety planning and connection to legal protections; collaboration with other professionals; connection to emergency housing; IPV education
	Mental health therapists	Diagnostic assessment; provision of trauma- focused psychotherapy; collaboration with other professionals; facilitates psychotropic medication initiation or transferring higher level of care (partial hospitalization) or different type of care (substance use; eating disorders) when needed; assess and respond to suicide and homicide risk
	Receptionist	Screening and scheduling of patients; creates welcoming milieu by phone and in-person; administers Promote Health; tracking of program evaluation data
	Attorneys	Legal consultation and referral on IPV-related concerns (e.g., divorce, custody)
Consultative team	Primary care physician	Addresses physical sequelae of IPV; evidence collection; connection with primary care
	Psychiatrist	Consultation regarding differential diagnoses and psychotropic medication needs
	Attorney	Facilitating community partnerships; IPV legal expertise; medical-legal partnership expertise
	Clinical psychologist	Hiring, coordination and integration of team members; partnering with medical center and community; budget management; evidence-based approaches to IPV treatment
	IPV survivor advocates and Community Advisory Board	Lived experience perspectives; pragmatic application of science; IPV education

and, as mentioned, (3). Employing a biopsychosocial treatment model created by our community advisory board of patient and professional stakeholders which incorporates multidisciplinary services in a health care setting supporting individuals who have experienced FIPV (23).

Our clinical team includes a social worker who provides assessment, resource connections (including occupational rehabilitation or assistance with other education and employment needs), crisis intervention, treatment planning,

and support; two advocates who provide safety planning and legal advocacy for safety; two mental health therapists who offer trauma-focused psychotherapy; and a receptionist, who creates a safe and welcoming environment for patients. We also have a legal consultation clinic available for those requiring legal assistance; lawyers meet with patients to provide education and resources on issues such as housing, custody, immigration and divorce, and connect them with lawyers who can continue to work with them when appropriate for free or for a reduced fee or payments directly to the legal provider depending on the patient's financial resources. Finally, we have a primary care physician available to assess medical needs, gather evidence, and facilitate connections to trauma-informed medical care when needed. All services provided are documented in the electronic health record to facilitate communication and collaboration. In the United States, most health care, including in academic health centers, is paid for through health insurance reimbursement. While there are various types of federal (i.e. Medicaid and Medicare) and private insurance payers, billing is required for health care clinicians to be reimbursed. This billing process can generate records and notices to third parties that can jeopardize safety, for instance, if the patient's insurance is paid for by an abusive partner or family member. Moreover, adequacy of insurance coverage varies, and many patients seeking health care services face significant costs due to high deductible payments or co-payments. To address these barriers, in HEAL only the primary care physician and therapists bill for the services per health insurance regulations in the United States, while we provide our other services free of charge. Thus, we absorb the costs for the initial visits with the social workers and advocates so those initial interactions can be completed without billing, ensuring the survivor is safe and can proceed to the next step. We have assembled a broad interprofessional consultative team to support the clinical team that consists of a psychologist, lawyer, psychiatrist, and our community advisory board led by three individuals with lived experience with FIPV. The supervisory team provides training, consultation and support for challenging situations through weekly case consultation meetings, monthly supervisors meetings, quarterly quality improvement meetings, and *ad hoc* in services and acute consultations as indicated; the frequency of involvement varies by need across these roles. Soliciting the expertise of individuals with lived experience has proven a critical part of ensuring we provide practical and trauma-informed responses.

When being seen at HEAL for services as an outpatient, an individual first speaks with our receptionist who schedules the appointment and describes what to expect from the initial appointment. When they arrive, the receptionist administers Promote Health, a psychosocial screening tool administered on an electronic tablet consisting of a broad range of validated screening questionnaires to assess needs and collect descriptive data on who is using our services. This purpose of this data collection is two-fold. First, it allows us to ensure that we assess a broad range of domains known to be relevant to individuals experiencing FIPV. Second, it allows us to understand the characteristics of those using HEAL, monitor progress over time, and identify programmatic areas for improvement. Domains



assessed include safety [e.g., Danger Assessment (33–35)], mental health [e.g., PHQ-9 (36); GAD-7 (37); Posttraumatic Stress Disorder Checklist (38, 39)], physical health [e.g., WHO-DAS pain items (40); sexual health], resource needs (e.g., housing, transportation, food, clothing, phone access), and barriers to treatment engagement [e.g., MEPS barriers to care (41)]. Once completed, Promote Health generates a resource list personalized to the patient's needs with services by zip code. The social worker then meets with the patient to assess goals and needs. As part of the appointment, they review the Promote Health results together. This appointment concludes with creation of a plan driven by the patient's goals and priorities; patients may or may not see the other team members depending on the plan. The social worker then collaborates with referring professionals, family members, and others involved with the patient's care, with the patient's permission.

Other HEAL team members can meet with the patient either immediately following this initial meeting or at a follow-up appointment, depending on the urgency of the needs, the patient's priorities, and the team members' availability. When a meeting with the advocate is initiated, the advocate offers safety planning, education regarding legal options, and, if needed, the opportunity to initiate an OP. When patients are unable to travel to court due to their health status (i.e. physical injuries, severe anxiety), we have state approval for the advocate and the individual to Skype with a judge to secure an OP rather than present in person. This accessibility allows substantially increased flexibility and opportunity for individuals to obtain OPs. For example, a pregnant woman admitted to the hospital for a gunshot wound by the father of her baby did not have to wait until she was discharged and could travel to court to initiate an OP. For those who can travel to court, the advocate can assist the individual in preparing the documentation needed and accompany the individual to court if desired. As a result, once the patient arrives at court, the case is expedited. The advocate provides outreach and support for the individual for the scheduled follow-up hearing two weeks later, if desired. The therapist provides diagnostic assessments and trauma-focused therapy as needed. The psychotherapists are skilled in a range of evidence-based approaches relevant for individuals who have experienced FIPV, such as Cognitive Processing Therapy for PTSD (42), Eye Movement Desensitization and Reprocessing Therapy (43), Cognitive Behavioral Therapy for Insomnia (44), and Group Interpersonal Psychotherapy for Victims of FIPV (45). For patients seeking therapy for reasons other than trauma-focused work or who may not be ready to start trauma-focused therapy, the therapists facilitate connecting them with someone else for care.

We also provide services for patients in the emergency department or inpatient units. The health care clinician identifies FIPV as a concern and reaches out to HEAL for assistance, and then the FIPV advocate travels to the patient, administers Promote Health bedside, reviews immediate legal options and resources, and initiates an OP by Skype if indicated and desired. The advocate will follow-up with the patient and unit staff for the duration of the individual's stay and assists with discharge planning. We next invite the patient to schedule a

HEAL Collaborative follow-up appointment post-discharge and to consider if there are other HEAL team members who could be of assistance.

## Education

Given the interdisciplinary nature of FIPV, educational opportunities are critical to fill the gaps for professionals of all disciplines working with FIPV. We also are eager to spark commitment to addressing FIPV across interprofessional groups, especially trainees. HEAL offers introductory level didactic trainings about FIPV, as well as more in-depth research and clinical opportunities for trainees with specialized interest. Requests come from throughout our academic health center, including the emergency department; human resources; chaplaincy services; the employee assistance program; the primary care physician network; social work program; behavioral health and substance use treatment programs; physical therapy and public safety. Presentations in our community have included family court; maternal and child health outreach workers; domestic violence organizations; local public radio and television; and other community-based organizations serving people at high risk for FIPV. Professionals in multiple contexts are eager to learn how to recognize FIPV, talk about it in a constructive way, and recommend appropriate responses so they can feel competent to ask and respond. The focus of these talks is on defining FIPV, how to assess for FIPV, and providing recommendations about how to respond once it has been detected, as well as informing our colleagues about HEAL as a resource.

At HEAL, we have provided graduate and undergraduate students training opportunities across diverse fields: medicine, law, business, public health, and humanities; their experiences vary based on their educational goals and needs. A business school graduate student team created a business model to support the sustainability of HEAL. Medical and graduate students have conducted secondary analysis on data collected at HEAL and consequently authored papers and posters. Others completed medical school service hours working directly with the HEAL team to help find best practice models, compile resource options, and offer opportunities to help the team develop expansion plans. The educational need is greater than our resources, and we are seeking ways to fund a full-time educator as an additional member of the HEAL team.

## Findings

To provide an overview of who has been utilizing HEAL, we report descriptive information on a subset of 365 patients who received services and completed Promote Health surveys. These data are from a sample of convenience based on a subset of those who completed the Promote Health as part of routine care. We utilized RedCAP to collect the Promote Health data and exported the data into SPSS. We conducted descriptive statistics after accounting for missing data to identify means, frequencies, and standard deviations. The University of Rochester Human Subjects Review Board approved this project as exempt from review since it was conducted as a program evaluation.

Respondents were on average 38.6 (12.1 SD) years old. Self-reported race was: 68% Caucasian/White ( $n = 249$ ), 24.4% African American Black ( $n = 89$ ), 2.5% American Indian/Alaskan Native ( $n = 9$ ), 2.2% Asian ( $n = 8$ ), and 7.9% other ( $n = 29$ ); 12.1% ( $n = 44$ ) were Hispanic/Latinx. Additionally, 93.7% were cisgender women ( $n = 342$ ), 4.9% were cisgender men ( $n = 18$ ), and 1.4% ( $n = 5$ ) were transgender women, transgender men, or gender-non-conforming individuals. A total of 85.8% ( $n = 313$ ) individuals identified as heterosexual, 10.1% ( $n = 37$ ) as bisexual, 3.0% ( $n = 11$ ) as gay/lesbian, and 1.1% ( $n = 4$ ) as other. Nearly half (44.9% ( $n = 164$ )) reported being single/never married, 23.6% ( $n = 86$ ) were currently married or living with a partner, 29.9% ( $n = 109$ ) were divorced or separated and 1.6% ( $n = 6$ ) were widowed. Individuals represented a range of incomes, with 56.8% ( $n = 201$ ) reporting a total household income of < US\$19,999, 21.2% ( $n = 75$ ), US\$20,000–39,999, and 22.0% ( $n = 78$ )  $\geq$  US\$40,000.

The mean depression score on the PHQ-9 was 9.3 (SD = 8.6) (score  $\geq 10$  indicates a likelihood of major depressive disorder), and 32.9% ( $n = 120$ ) reported suicidal or death ideation; mean anxiety score on the GAD-7 was 8.4 (SD = 7.8) (score  $\geq 10$  indicates at least moderate anxiety); and mean PTSD severity on the PTSD Checklist was 13.2 (SD = 10.6) (score  $\geq 14$  indicates active PTSD). The mean Danger Assessment score was 7.8 (9.3 SD) (score  $>8$  indicates significant risk of being harmed or killed).

Given the mean age of 38.6 years, we have determined that we need greater outreach to educate older people about the HEAL Collaborative resource. Such venues might include community programs targeting older adults, faith communities, local recreational clubs, and social services agencies, such as our county welfare agency, who all provide services to older populations. Our sociodemographic characteristics regarding race and ethnicity largely mirror our county composition. We are also underserving men. We see the need to do additional outreach to male serving organizations, such as fraternal agencies, local business communities, and local unions.

The substantial risk of danger highlighted the need for us to ensure our suite is located in a physically secure environment and to develop procedures to maximize the safety of our patients and our staff. Our mental health findings suggest nothing new – many of our patients show symptoms worthy of clinical assessments for posttraumatic stress disorder, anxiety and depressive symptoms. Also not surprising, but nonetheless concerning, is the high rates of suicidal or death ideation. It is common for abused individuals to feel hopeless in the face of abuse. However, our community advisory board members believe it is the ability to partner with myriad agencies through a collaborative that can restore hope. The journey was not easy – but is demonstrating success.

Initially, we identified many system barriers to implementation. Our system barriers were identified through biweekly case conferencing meetings, administrator meetings, supervisor meetings, our community advisory board meetings and patient feedback. The thoughts reflected below are the themes which resurfaced as agreed upon by the authorship team. The academic health center administration was hesitant to embrace HEAL as a program initially, particularly given

hesitancy to view FIPV as a focus as well as potential financial costs and other risks involved. Safety needs required close partnership with the health center's public safety department. Yet many clinicians were already seeing these patients without knowing violence was an issue. Privacy and legal concerns by community FIPV agencies to have the HEAL clinicians record their work in the electronic health record and collaborate closely with other professionals needed to be understood and addressed. Over time, our integration and collaboration has improved tremendously, primarily by establishing partnerships, developing trust, creating shared commitment, clarifying HEAL's identity and the team members' roles, and providing education about the roles. Areas of overlap among the HEAL team members and their skillsets (e.g., safety planning; supportive counseling) created some tension early on and clear workflows and roles and responsibilities were established. In addition to writing notes to document the visit in the electronic health record, we have an internal electronic referral form in the electronic health record making it easier for clinicians in our health care center to refer to HEAL. Lastly, we have a protocol with public safety to promote the safety of our patients served and the HEAL team. Each of these steps requires ongoing negotiation, as well as evolving our shared values and commitment with interdependent roles. When the 21<sup>st</sup> Century CURES Act (46) was implemented entitling all patients to have immediate access to their electronic record health documentation, we developed a process to assess if it was safe for patients to have notes released for them to view and/or ensure it was not triggering of their symptoms so we could offer the option to opt out of having their notes available when indicated.

The greatest ongoing challenges with HEAL have involved the culture shifts needed for this innovative endeavor for which no template exists; determining financial sustainability given that most of our services are not billable within existing health insurance structures; and developing our own realistic expectations. Not surprisingly, these issues are all ongoing. Given that addressing FIPV is not typically considered within the domain of health care, several years of meetings and negotiations were required with our New York State legal system, local court, institutional counsel's office, the privacy office, local service and FIPV advocacy organizations, and the University of Rochester Department of Psychiatry, housing HEAL. As laws and funding streams change, so do the parameters within which we must function. Within all this other work, the challenge of developing a sustainable business model for HEAL remains. Reimbursement for psychotherapy is not covered for treatment of a diagnosis "domestic violence." Not all individuals meet criteria for a physical or mental health diagnosis and likely would not appreciate completing a diagnostic interview if they are not interested in psychotherapy. Further, a sizeable proportion of those we serve cannot safely use their health insurance for risk of others finding out they are seeking care. Relying on billable activities to generate revenue to cover the services for which we do not bill also limits the ability to expand our educational and clinical services. For example, we would like to be able to provide more educational and prevention activities. We are exploring ways to ensure HEAL can be self-sustaining outside of

a fee-for service model. Success in this area will be essential to the continued survival of HEAL.

We have experienced other challenges at HEAL. Staff and patient safety was highlighted as a priority when we discovered one patient brought a weapon with her to her sessions and another was being stalked by a dangerous ex-partner. We continue to partner closely with public safety to develop and update our physical space, policies and procedures (e.g., locked access; checking in weapons with the public safety office; instructing patients to park in distant lot and leave their phone in the car if needed). Complex situations such as bidirectional abuse or those seeking court-mandated care challenge our understanding of who we should support. We ultimately decided we welcome anyone who self-identifies as having experienced FIPV and that it is not our team's role to judge the validity of patients' narratives.

COVID-19 also presented challenges to how we offer care at HEAL, as it did to all health care and FIPV service delivery. Our priority was to find ways to make our services available while protecting individual and staff safety and health. We initially moved all of our outpatient services to telehealth and developed a script to assess each individual's access to privacy at the initiation of each appointment. We provided education and support to other programs about how to consider safety while delivering telehealth services. We also started to offer services in the emergency department and inpatient units virtually via electronic tablet. We learned to administer Promote Health virtually in advance of scheduled appointments (although it has been completed less consistently due to implementation barriers). Over time we have shifted to a hybrid model, offering both remote and in-person visits depending on patient preference, current risk status related to the pandemic, and the safety and access of telehealth intervention. In our hybrid model, outpatients are invited (but not required) to attend their initial visit on-site so we can better assess safety and then develop an in-person or remote follow-up plan based on that particular individual's needs. Despite an initial drop in HEAL utilization in March 2020, within two months we resumed our initial rates, and referrals have continued to increase. We find many individuals have benefitted tremendously from the increased flexibility and access offered by remote appointments. Yet we continue to struggle with how to meet the growing demand and intensity of our community's needs.

As part of a larger study, we interviewed individuals who had utilized HEAL prior to COVID-19. The Short Explanatory Model Interview [SEMI (47)] is a semi-structured questionnaire developed by Lloyd and his colleagues that includes a coding manual and is based on Kleinman's theory on Explanatory Models (48). We used the SEMI to ascertain HEAL patients' explanatory models with relation to FIPV. We audiotaped and transcribed the interviews into Word documents and an interdisciplinary team analyzed the results documenting patients' HEAL experiences. Using a codebook based on the SEMI, we analyzed the transcribed interviews from HEAL patients. Preliminary findings document two extraordinary things: there were no negative patient testimonies and patients overwhelmingly

remarked how exceptional their HEAL experiences were. Two illustrative examples follow:

"[It]'s a really great place for women to go, and deal with their trauma. It's a really nice setup, **they have the legal and the social work, and the counseling, all in one.** And it's a kind of secure place...it's been just a really positive kind of experience. They've always been help."

"Like they literally tried every avenue they could and you know like I said even [therapist] went above and beyond, you know I won't go through the whole story but **she even contacted public defenders in that county and legal aid so she actually got me my first lawyer.**"

The SEMI interviews revealed that HEAL's team-based approach, accepting stance by the clinicians, and access to a physically and emotionally safe space were of particular importance to the HEAL patients interviewed.

## DISCUSSION

We have learned individuals experiencing FIPV and their health care professionals are eager to utilize the services offered at HEAL. We receive frequent acknowledgments of the gaps HEAL is filling from individuals, health care clinicians, and community organizations. Examples of some feedback include: "This has been a very challenging case and appreciate everyone's help!", "Thank you so much for this thorough reply - I really appreciate all of these ideas!"

We have come to appreciate the need for patience, time-intensive conversations, and, most importantly, a spirit of shared dedication to create a team that can offer services that are accessible, supportive and responsive to those who need them. Bringing this spirit of shared goals allows us to struggle together to attain meaningful consensus while capitalizing on our unique skills and strengths.

Having perspectives from individuals with lived FIPV experience was critical to the development and implementation of HEAL. For example, we debated the competing values of protecting privacy of individuals who have experienced FIPV by not sharing clinical information with other professionals vs. using a collaborative team approach to facilitate coordinated and trauma-informed support. We were able to turn to our colleagues with lived experience and ask them to describe the merits and risks of each of these approaches. Through our conversations together, these stakeholders emphasized the need for their health care professionals and others to understand their full range of needs within the context of carefully obtained informed consent. We were able to reach consensus that allows for close collaboration with the interprofessional team for individuals who do provide consent. Our stakeholders also participated in a discussion about safety and information about the level of detail and language that would be included in their electronic health record or other communication.

## Acknowledgment of Any Conceptual Or Methodological Constraints

The findings and discussion here are based on clinical data collected for treatment, safety decisions, and program evaluation. Moreover, they do not include outcomes. We are eager to take the next steps to conduct a longitudinal evaluation of HEAL's effectiveness to determine if it is replicable and scalable. Using lessons learned from HEAL, we can move toward laying the groundwork for broad dissemination and implementation.

## Conclusions

Individuals experiencing FIPV present at courts, shelters, health care centers, and social service agencies which maintain separate data collection systems and strict confidentiality mandates. In the mental health setting, we tend to focus exclusively on treating symptoms related to psychiatric diagnoses, and inadvertently can neglect the social, safety and physical health factors contributing to individuals' presentations. HEAL helps to bring these disconnected systems together.

FIPV-focused work is challenging. Many of the HEAL patients have truly catastrophic life experiences. Some present with severe physical injuries that are difficult to witness and all are invited to describe their abuse experiences in detail. Outcomes are not always what was hoped for by the individuals nor their health care clinicians. A team-based approach is important not only because of the range of skills required, but also because of the shared support needed. Working as a team allows for all members to hold both the pain and the successes together. We have learned that by creating space as a team to acknowledge and address vicarious traumatization and compassion fatigue together, we are better able to sustain the work.

Launching HEAL has taken a village of individuals with diverse training, experiences and perspectives committed to the shared goal of offering effective team-based biopsychosocial care for individuals experiencing FIPV. Expanding on the MLP model to incorporate integrated interprofessional support offers a new person-centered model of care for individuals experiencing FIPV. The educational opportunities are great and continuing to develop. While laying the foundation for this work has been necessarily challenging, it has been tremendously rewarding to our interprofessional team of clinicians, researchers, and advocates. The foundation is now in place to better respond to the complex needs associated with FIPV, and to build a system of innovation and evaluation into this experience.

## DATA AVAILABILITY STATEMENT

Due to the sensitivity of this being patient data, a deidentified data set supporting the conclusions of this article will be made available with the appropriate human subjects research approvals from both institutions.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Rochester Research Subjects Review Board. The Ethics Committee waived the requirement of written informed consent for participation.

## AUTHOR CONTRIBUTIONS

MW, EP, MR, and CC contributed to conception and design of the paper. IJ organized the database. IJ and HC performed the statistical analysis. EP wrote the first draft of the manuscript. MW, MR, and CC wrote sections of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

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# Applying Care Coordination Principles to Reduce Cardiovascular Disease Risk Factors in People With Serious Mental Illness: A Case Study Approach

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People with serious mental illness (SMI) have a 2–3-fold higher mortality than the general population, much of which is driven by largely preventable cardiovascular disease. One contributory factor is the disconnect between the behavioral and physical health care systems. New care models have sought to integrate physical health care into primary mental health care settings. However, few examples of successful care coordination interventions to improve health outcomes with the SMI population exist. In this paper, we examine challenges faced in coordinating care for people with SMI and explore pragmatic, multi-disciplinary strategies for overcoming these challenges used in a cardiovascular risk reduction intervention shown to be effective in a clinical trial.

**Keywords:** serious mental illness, care coordination, care management, cardiovascular risk, behavioral coaching

## INTRODUCTION

People with serious mental illness (SMI) experience excess mortality at rates 2–3 times higher than the general population, equivalent to a loss of life of 10–20 years (1, 2). Cardiovascular disease (CVD) is the leading cause of death for this group and is largely modifiable by addressing risk factors, including obesity, diabetes, hypertension, dyslipidemia, tobacco use, poor diet, and physical inactivity- which are highly prevalent in populations with SMI (1, 3, 4). Use of antipsychotic medications also contributes to metabolic changes with weight gain, hyperglycemia, and dyslipidemia (5).

People with SMI often face significant challenges accessing quality healthcare, including high rates of poverty, housing instability, unemployment, and interactions with the criminal justice system (6–8). Moreover, people with SMI are less likely to receive guideline-concordant care compared with the general population (9–11). For example, they are less likely to receive annual screenings for diabetes-related complications or recommended medications after a myocardial infarction (12–15). Cognitive dysfunction, communication challenges, and low health literacy may further impede care delivery to people with SMI (6, 16, 17). Finally, specialty mental healthcare has historically been delivered separately from physical healthcare services and created challenges in coordinating services for this vulnerable population (10, 18, 19).

Care delivery models have sought to better integrate delivery of behavioral and physical healthcare, but these models have faced challenges. Models such as Collaborative Care (20–22) or the Patient Centered Medical Home (23–25), where behavioral health is integrated into primary care settings, may have primary care providers (PCPs) who lack experience in treating individuals with SMI (24). In the Behavioral Health Home (BHH), where the coordination of care for physical healthcare is centered in the specialty mental healthcare setting (26, 27), behavioral health providers may not feel equipped to address CVD risk factors (28).

Given the lower rates of guideline-concordant care and persistent mortality gap for people with SMI, it is critical to understand successful examples of care coordination around physical health conditions. Yet descriptions are scarce regarding populations with SMI. In this paper, we use a clinical vignette of an individual with SMI, who was enrolled in a successful cardiovascular risk reduction intervention trial, to highlight challenges and opportunities in delivering guideline-concordant care for people with SMI and multiple CVD risk factors. We describe the care management and care coordination processes employed within the clinical intervention and future implementation lessons.

CARE MANAGEMENT AND CARE COORDINATION

Care management and care coordination are complementary approaches to deliver healthcare across multiple providers and settings (Table 1). Care management is a team-based practice approach to align and manage health services according to a population’s needs (29, 30). Strategies target providers (e.g., health risk assessment training, electronic decision support) or patients (e.g., health coaching, brochures) and involve a multi-disciplinary team of providers. Meanwhile, care coordination organizes patient care activities across participants involved with a patient’s care (e.g., providers, patient, supporters of patient) (31). Activities include establishing accountability, communicating and sharing knowledge, facilitating transitions of care, assessing the patient’s needs and goals, developing a care plan, monitoring and follow-up care, supporting patients’ self-management goals, linking to community resources, and aligning resources with patient and population needs. This model has been shown to improve chronic disease care quality for the general population (29, 32, 33) and for those with SMI (34–38).

CARDIOVASCULAR RISK REDUCTION INTERVENTION: IDEAL TRIAL

The NHLBI-funded IDEAL trial was a successful 18-month randomized clinical trial that tested a comprehensive cardiovascular risk reduction program incorporating care management, with an emphasis on health behavior coaching, and care coordination at four community mental health outpatient programs for people with SMI who had at least one CVD risk factor (39). It demonstrated an overall reduction in

TABLE 1 | Care management and care coordination activities from the Agency for Healthcare Research and Quality frameworks (30, 31).

Care management	Prioritize one-on-one encounters Conduct training Involve physicians Involve informal caregivers Provide health coaching and discrete self-management skills
Care coordination	Assess patient needs and goals Create proactive care plan Support patients’ self-management goals Monitor and follow-up as patient’s needs change Establish accountability Communicate and share knowledge Help with transitions of care Link to community resources Align resources with patients’ needs

10 year CVD risk reduction by 13% in the intervention group compared to control (40).

The intervention’s theoretical framework draws upon a biopsychosocial approach and leverages behavioral change strategy and person-centered care in addressing physical health (39). Specifically, the 269 adult participants randomized to the intervention received a care plan tailored to their specific CVD risk factors (hypertension, diabetes, dyslipidemia, tobacco use, obesity), which was delivered jointly by a health coach and nurse. The health coach, based at the community mental health organization, conducted one-on-one sessions weekly for the first 6 months and then at least every 2 weeks thereafter. Sessions focused on individual health behaviors and collaboratively agreed upon goals. The nurse met with participants around CVD risk factor education, medication counseling, and accompanied participants to physical health visits with physicians as needed. In addition, the nurse coordinated care with physical and behavioral health providers (defined broadly as any healthcare worker including pharmacists, social workers). For participants interested in smoking cessation using pharmacotherapy, the nurse coordinated with participants’ psychiatrists for varenicline, bupropion, and/or nicotine replacement therapy prescriptions (39). Both the health coach and nurse used a motivational interviewing approach and solution focused therapy techniques to facilitate health behavior change with participants (39).

The institutional review boards at Johns Hopkins University and Sheppard Pratt Health System approved the clinical trial. The patient provided permission to be featured in this clinical vignette, and identifying initial was changed to protect privacy.

CLINICAL VIGNETTE

Ms. E., a participant in her mid-40s, had a medical and psychiatric history notable for hypertension, type 2 diabetes mellitus, tobacco smoking, obesity, and schizophrenia. Significant medications were metformin 750 mg twice daily, propranolol 10 mg as



needed, clozapine 300 mg daily, haloperidol 5 mg twice daily, fluoxetine 60 mg daily, valproic acid 1,500 mg daily, clonazepam 0.5 mg three times day, and benzotropine 0.5 mg daily. On study enrollment, laboratory values were remarkable for an elevated A1c of 7.8% (reference range <5.7%), total cholesterol of 257 mg/dl (reference range: 0–200 mg/dl), and low-density lipoprotein (LDL) of 151 mg/dl (reference range: 0–100 mg/dl) with an estimated 10-year risk of 9.2% of having a heart attack or stroke based on atherosclerotic cardiovascular disease risk factors. Ms. E. lived in a residential program, where staff helped to schedule transportation.

On study entry, Ms. E. met with the health coach and nurse and identified diabetes self-management and tobacco smoking cessation as her primary health goals. Together, the health coach, nurse, and Ms. E. formulated a care plan to reach these goals. She met with the health coach weekly where she expressed anxiety around quitting smoking and her worry about developing cancer. By the first month, she set a quit date and focused on smoking cessation through behavioral change and pharmacotherapy, consistent with an evidence-based approach for persons with SMI (41). The nurse then coordinated earlier receipt of varenicline for smoking cessation as Ms. E.'s regular appointment with the prescribing psychiatrist was several months away. Ms. E. took the prescribed varenicline, continued to receive behavioral counseling for smoking cessation, and was able to quit smoking for 4 weeks.

When Ms. E. began smoking again, with inconsistent use of varenicline, she and the health coach identified triggers that led to relapse (e.g., feeling angry), potential solutions, and set a new quit date. They focused on discrete strategies, such as avoiding situations where she may be offered cigarettes or taking deep breaths. Ms. E. restarted varenicline and met with the coach weekly. However, after a series of falls, a director of the mental health center asked to discontinue varenicline out of concern that varenicline contributed. The nurse met with the director to discuss that varenicline was unlikely the source of the falls and emphasize that Ms. E. was at high risk for tobacco relapse. They agreed that Ms. E. could continue the medication. When Ms. E. underwent surgery for an ankle fracture, the psychiatrist held varenicline in anticipation of other medication changes in the perioperative period. After surgery, Ms. E. elected not to continue on varenicline; she successfully refrained from smoking and met bi-weekly with the health coach. After she was hospitalized for a mental health crisis, Ms. E. and her coach reviewed triggers for smoking and strategies to address triggers. Ms. E. was successful in remaining tobacco free for over a year at study end.

Attaining glycemic control was challenging for Ms. E. She met with the health coach weekly around diabetes self-management skills and received educational materials with high readability and simple messaging, such as "Avoid sugar drinks," or "What counts as a fruit." Ms. E. and her coach reviewed her blood glucose logs and foods that she had eaten. She found it difficult to regulate portion size and to remember to choose healthy snacks (e.g., sugar-free candies as a replacement for cigarettes). The coach helped her to make a list of foods that elevated blood sugars. Ms. E. also met with the nurse and reviewed diabetes self-management, medications, and prepared questions in advance

of visits with her PCP. At the visit, the nurse advocated for initiation of statin therapy, consistent with guideline-concordant lipid management in persons with diabetes (42). Ms. E. was started on pravastatin.

Throughout the following year, Ms. E. worked closely with the health coach to review food choices, increase physical activity levels, and consistently take medication. She continued to struggle with changing dietary habits—eating when stressed, eating large portions, and eating when not hungry. Ms. E. set personal goals of cutting out sugary beverages and decreasing foods high in carbohydrates. After she fractured her ankle, she worried about gaining weight. She and her coach reviewed diabetes self-management topics and aligned smoking cessation strategies with smart snacking choices. Ms. E. then set defined goals, such as choosing water instead of juice. The nurse also coordinated with the residential counselor to reschedule canceled medical appointments, arrange transportation, and to obtain regular blood monitoring of glucose levels and cholesterol. At her 18-month follow up, Ms. E. had improved glycemic and cholesterol control with an A1c of 6.5% and an LDL of 65 mg/dl on an increased dose of metformin (1,000 mg twice daily) and pravastatin 40 mg daily. Over the study, 65 encounters (78 encounters anticipated per study protocol) were documented for Ms. E. between the coach and the nurse, of which 10 involved coordination with providers outside of the community mental health program.

## DISCUSSION

This vignette of an individual with SMI who successfully stopped smoking tobacco and achieved glycemic control with the assistance of a health coach and nurse was drawn from an 18-month clinical trial in a community setting. It highlights the real-world challenges and the intensity of resources needed to reduce CVD risk factors for persons with SMI.

### Assessing Patient Needs and Goals and Creation of a Care Plan

The care plan reflected the participant's health goals and CVD risk factors, and whether guideline-concordant care was due. It also included goals that the patient may not have prioritized (e.g., weight loss). Identifying the primary location of meals (e.g., residential facility, family) helped the health coach and nurse tailor nutrition-based education sessions (e.g., diabetes-focused) and took into account the patient's socioeconomic concerns.

Involving individuals with SMI in the creation and implementation of the care plan is fundamental to patient-centered care. This includes defining what is important to them and actions that they are willing or not to take. Motivational interviewing has been a successful approach for engaging people with SMI around health behavior change goals (43). Given that persons with SMI experience stigma within healthcare settings (16), it is important that their voice is heard from the onset and throughout care delivery.

## Supporting Disease Self-Management and Responding to Patient's Ongoing Needs

Ms. E. experienced physical health setbacks and a mental health crisis during the intervention. Intervention staff checked in frequently and adapted coaching sessions to her evolving needs and concerns. They recognized that the ankle fracture impacted her physical activity levels and influenced her cravings for snacks and cigarettes. During transitions, the health coach addressed arising anxieties and helped Ms. E. to set well-defined goals.

Our experience found continuous engagement between trial staff and participants increased participants' confidence with self-management skills. As people with SMI may experience cognitive dysfunction, disability and low health literacy, materials were tailored to improve readability and to account for these considerations (6, 44). Some participants benefited from repetition of topics, updates or selecting new targets of behavior changes. Health coaches and trial staff advocated on participants' behalf to address organizational-level challenges. For example, one participant noted that he walked past staff members who were smoking when he entered the mental health clinic. Trial staff then spoke with clinic leadership to move the designated smoking area away from the front entrance, which was a culture shift for employees. Trial staff also worked with residential facility managers to change purchasing habits (e.g., increase diet soda availability).

In addition, goal setting, and skill building reinforced a behavioral change strategy well-suited to people with SMI (43, 45). We found that aligning multiple health goals was effective. For Ms. E, she and the health coach discussed using sugar free gum and candies to address oral cravings for smoking cessation while being mindful of underlying diabetes. Similarly, health coaches encouraged setting a discrete food goal (e.g., additional serving of vegetables) that would parallel a physical activity goal (e.g., number of steps) for weight loss.

## Prioritizing One-on-One Encounters

This intervention had a high frequency and intensity of encounters between the participant, health coach, and nurse. Topics were reinforced over time, emphasized specific skills, and broke materials into small units. Coaches and nurse met participants where they were at, based on their psychiatric condition, cognitive skills, and behavioral change goals.

In addition, each health coach was embedded within a community mental health center and met with participants one-on-one. This approach likely improved rapport and facilitated communication between the coach and behavioral health team. Literature suggests that in-person encounters for care management are more effective than telephone encounters (46). Given the growth of telemedicine during the COVID-19 pandemic (47), programs should consider hybrid models for care management and care coordination services.

## Establishing Accountability

Care management and care coordination are inherently team-based practices, and successful teams need to have defined roles and responsibilities (48). During this intervention, accountability occurred when providers identified discrete expectations and

goals, checked in regularly with one another, and closed feedback loops (31). The health coach and intervention nurse developed and implemented the care plan with the participant. The health coach led discussion on self-management skills and health behavior counseling, with regularly scheduled and *ad hoc* check-ins with participants. The nurse acted as a liaison with behavioral health providers, PCPs, medical sub-specialists, family, and residential program staff. The nurse sent an introductory letter about the intervention to PCPs and sometimes attended office visits. This approach helped to facilitate knowledge of how the nurse and health coach could enhance a participants' existing care plan. For example, the nurse measured participants' blood pressure and relayed that information to the PCP, thereby facilitating ambulatory blood pressure monitoring. Additional activities included advocating for aggressive management of CVD risk factors (e.g., statin prescription for cholesterol management) and educating caregivers about how to support individuals with SMI with health goals. Both the health coach and intervention nurse provided in-person and email updates to behavioral health staff of the progress of participants, if requested. If concerns related to social determinants of health arose (e.g., food insecurity), the health coach and/or nurse reached out to staff at the mental health center, which had existing ties with social services. This process required knowledge and understanding of who the participant was, their support network and living situation. Future work will need to incorporate clear expectations for roles and responsibilities and opportunities for formal and informal check-ins with team members.

## Communicating and Sharing Knowledge

When caring for people with SMI, it is essential that communication occur between the patient, behavioral health providers, and physical health providers and that communication loops are closed to reduce potential miscommunications. Transitions of care, are particularly high-risk settings (49). When Ms. E. had a somatic and later a mental health-related hospital admission, the health coach and nurse tailored counseling to match her needs to help to stay consistent with her health goals (e.g., smoking cessation).

The nurse and health coach regularly communicated in-person, by phone, and email. Frequent communication occurred with behavioral and physical health providers, with more open communication correlated to improved control of CVD risk factors for participants. However, challenges around communication arose. No shared electronic health records were available between behavioral and physical health providers, a problem observed in care coordination programs across other healthcare systems (50). Intervention staff relied on phone messages or faxes for communication with external providers, sometimes leading to delays in having messages returned from providers outside of the mental health center.

## FUTURE DIRECTIONS

This vignette illustrates how care management and care coordination processes were successfully employed to reduce CVD risk factors for person with SMI within the formalized

structure of an intervention. By outlining the frequent, high-intensity care coordination and care management processes required to care for patients with SMI, we filled a gap in the literature. It is imperative that health systems implement protocolized care coordination and care management processes to address CVD risk factor care for populations with SMI.

Future program implementation may wish to start in settings that care for high number of individuals with SMI. Enhanced primary care models and BHHs are natural settings because they focus on populations with SMI, and in the case for BHHs, have an existing funding through the Medicaid waiver program (27, 51). Models that integrate somatic and behavioral health across acute and outpatient settings may also be of interest given their focus on individuals with SMI to maintain overall health after hospital admission (52).

Implementation plans will need to include accountability and address communication gaps between behavioral and physical health providers. For behavioral health providers, addressing physical health concerns may feel out of scope for their usual practice; therefore, it is essential that implementation plans include connections with (a) PCPs who can lead on physical health management, and (b) care managers and health coaches who work across behavioral and physical healthcare sectors.

Finally, financing remains a challenge. Alternative payment models, such as Accountable Care Organizations or the Medicaid waiver program, could provide funding streams to support care coordination as described here (53, 54). Future policies will need to provide support for health systems to implement these processes. This vignette is a first step in highlighting the discrete,

intensive care coordination and care management processes needed to care for populations with SMI and considerations for program implementation and sustainability.

## DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Johns Hopkins University School of Medicine. The patients/participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

## AUTHOR CONTRIBUTIONS

KM and GD contributed to the conception and design. KM wrote the first draft of the manuscript. All authors contributed to the manuscript revision, read, and approved the submitted version.

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# Practical Opportunities for Biopsychosocial Education Through Strategic Interprofessional Experiences in Integrated Primary Care

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Even with the expansion of primary care teams to include behavioral health and other providers from a range of disciplines, providers are regularly challenged to deliver care that adequately addresses the complex array of biopsychosocial factors underlying the patient's presenting concern. The limits of expertise, the ever-changing shifts in evidence-based practices, and the difficulties of interprofessional teamwork contribute to the challenge. In this article, we discuss the opportunity to leverage the interprofessional team-based care activities within integrated primary care settings as interactive educational opportunities to build competencies in biopsychosocial care among primary care team members. We argue that this approach to learning while providing direct patient care not only facilitates new provider knowledge and skills, but also provides a venue to enhance team processes that are key to delivering integrated biopsychosocial care to patients. We provide three case examples of how to utilize strategic planning within specific team-based care activities common in integrated primary care settings—shared medical appointments, conjoint appointments, and team huddles—to facilitate educational objectives.

**Keywords:** interprofessional education, biopsychosocial, integrated primary care, shared medical appointment, huddle

## INTRODUCTION

Providing whole-person care that addresses the complex array of biopsychosocial factors contributing to patients' health concerns is a perpetual challenge in primary care (PC). For instance, a patient can present with psychological distress from depression and/or food insecurity, which can drastically impact diabetes management. These factors can, in turn, also contribute to the patient's decisions regarding engagement in certain health behaviors, such drinking alcohol, that may negatively impact chronic medical conditions. This example clarifies why primary care providers (PCPs) have been encouraged to switch from traditional models of focusing only on biological factors of health toward the biopsychosocial model, which recognizes biological, psychological,

and social factors and their interactions that contribute to health and well-being (1). However, the limits of expertise for any one PC team member are stretched by patients presenting with a range of medical concerns that are often further complicated by psychological distress and/or unmet social needs (2). In addition, PC team members are frequently required to rapidly shift clinical practices to stay up-to-date with the latest research (3). For instance, research has demonstrated the value of using psychological treatments for several health concerns [e.g., insomnia (4), chronic pain (5)]. Yet, PCPs struggle to embrace new clinical practices and engage patients in these new treatments (6). The shift toward team-based care within PC settings (7) is intended to help address these gaps and improve the quality of patient care by adding members with complementary and specialized skillsets to teams, such as behavioral health providers (BHPs; e.g., psychologists, social workers) (8). These additional team members have the skills to support the PC team in improving their approach to talking to and directly helping patients.

However, simply embedding additional providers in PC does not yield instant success in overcoming barriers to delivery of biopsychosocial care. High-quality, patient-centered care that recognizes the biopsychosocial contributions to patients' presenting concerns will not be delivered unless teams move beyond a referral model, in which the factors contributing to disease are compartmentalized and handled separately by different providers. Instead, all providers need to embrace the biopsychosocial model and work cohesively as a team, and collaboratively with the patient, to recognize, support, and implement strategies jointly targeting biopsychosocial factors. The purpose of this article is to discuss strategies to leverage interprofessional clinical experiences within integrated PC settings to facilitate interactive, biopsychosocial education for providers that ultimately improves patient care. We present three approaches using study protocols currently being piloted.

## Rationale

PC education begins in healthcare training programs and is supplemented by continuing education. Many of these educational opportunities are provider- or discipline-specific, use formal learning approaches [i.e., organized didactic learning events (9, 10)], require time separate from direct patient care, and result in small-to-moderate changes in provider behavior (11–13). Given these limitations, there is a need for creative solutions to assist PC team members, especially within the context of biopsychosocial approaches to care.

Building on the framework of social learning theory (14), leveraging the presence of the interprofessional team can provide an innovative way to achieve interactive education in which skills can be learned via observation and modeling from others within the team while delivering patient care. This allows multiple team members from a range of disciplines to learn through informal and experiential interprofessional education during direct patient care (15) without requiring providers to carve out additional time. Interprofessional team education with trainees has been shown to increase knowledge, teamwork, satisfaction, and improve delivery of care to patients (16).

This approach of learning through team-based care activities also allows for the PC team members to not only gain new knowledge on specific presenting concerns, but also further develop their skills in the team processes that are key to collaboratively providing integrated biopsychosocial care to patients. Salas and colleagues (17) have identified several essential elements that underlie successful teamwork, such as communication, coordination, and cooperation. Engaging PC teams in specific activities that require team members to work together in a structured way provides real-world opportunities to improve all these skills during clinical activities.

## Types of Team-Based Activities That Can Serve as Educational Opportunities

Several team-based direct patient care activities that already occur within integrated PC settings can be strategically infused with interactive, interprofessional, biopsychosocial education. Examples include: shared medical appointments (SMAs; also known as group medical visits) in which the PCP and other members of the team such as the embedded BHP meet with a group of patients with a common presenting concern [e.g., (18)]; team huddles, “a brief, frequent form of structured communication among members of the PC team” to discuss patient care and maximize efficiency (19); and conjoint appointments in which two providers (e.g., PCP and the embedded BHP) meet jointly with a patient to discuss a specific concern (20). All three team-based examples are patient-care activities that can also facilitate education. These activities are well-suited for, and enhanced by, a biopsychosocial lens as they often consider a range of biomedical, psychological, and social factors relevant to patients and utilize a range of interventions including psychoeducation, medication management, and evidence-based behavioral strategies (21).

## Strategic Interprofessional Education

Strategic planning is necessary to optimize the interprofessional educational yield of these team-based care activities, as social learning theory suggests the activities need to not only include observation/modeling, but also attend to cognitive processes (i.e., motivation, attention, retention, and reproduction) to maximize learning (14). The topic of the team-based care activity needs to be relevant and meaningful for all team members involved to help motivate learning (22). The specific educational objectives should be identified ahead of time. As our protocols detailed below highlight, leveraging activities that are already a part of providers' daily provision of direct patient care and identifying specific educational objectives that are of interest to providers increases the direct relevance of the information, which improves adult learning (23). In addition, the team-based activity needs to ensure interactive learning can take place through either observation and/or simulation. The team-based activity also needs to go beyond shared learning or working in tandem to engage providers in interprofessional collaboration for informal and experiential learning to take place (22) while simultaneously attending to interprofessional team processes, such as role clarity and communication. Therefore, specific strategies to encourage the team to attend to the material one another are sharing and

work together toward shared objectives are key. Finally, the team-based activity needs to provide opportunities for the team members to reproduce the learned information. The three team-based activity protocols below highlight strategies to integrate interprofessional biopsychosocial education and clinical care into routine PC practice.

## THREE DIFFERENT APPROACHES/PROTOCOLS

### Interprofessional Structured Shared Medical Appointment for Chronic Pain

Chronic pain is highly prevalent in PC, yet access to specialty pain clinics is limited (24), leaving most chronic pain patients [i.e., 52%; (25)] treated by PCPs. However, PCPs receive little education regarding the treatment of chronic pain, particularly from a biopsychosocial (compared to biomedical) perspective (26, 27). PCPs often report feeling the least confident in their ability to manage chronic pain patients compared to other providers [e.g., specialty pain physicians; (25)] and that treatment of chronic pain is a substantial source of dissatisfaction (28).

Less formal experiential education strategies, particularly those incorporating interprofessional consultation, improve quality of care (29) and enhance knowledge (16). If implemented effectively, experiential interprofessional education strategies may help improve management of chronic pain specifically (26). Based on previous research demonstrating the efficacy of SMAs for chronic pain (30, 31), we examined an SMA to address chronic pain as a clinical demonstration in a United States Veterans Health Administration (VHA) PC clinic. This was a 5-session, closed, ~75-min group visit delivered across 7 weeks for patients ( $n = 6$ ) with musculoskeletal chronic pain. The SMA content focused on two evidence-based approaches: medication education and management delivered by a clinical pharmacist and PCP (32) and Cognitive-Behavioral Therapy for Chronic Pain (CBT-CP) delivered by a BHP, which improves pain intensity and pain self-efficacy (5).

We incorporated additional structure into the SMA to maximize interprofessional informal and experiential learning among the PCP, clinical pharmacist, and BHP on the provision of evidence-based biopsychosocial chronic pain management. The educational objectives were to improve the PCP's knowledge and use of biopsychosocial approaches to pain management and to improve their knowledge of pain medication management strategies. A 25-min team briefing was held prior to the initial SMA appointment to ensure all team members knew one another and their specific role in the SMA, as well as provide an opportunity for members to review aspects of evidence-based chronic pain management together. The PCP and BHP co-lead the introduction to some material, which allowed the PCP to observe the BHP presenting the biopsychosocial model of pain (SMA appointment 1) and cognitive aspects of CBT (SMA appointment 4) to promote the PCP's experiential learning of these key aspects of care. The clinical pharmacist was asked to review each SMA patient's medical chart and provide recommendations to the PCP prior to the first and

fourth SMA visit. These recommendations were discussed among providers, thus allowing for experiential learning of evidence-based pain medication management strategies, a specialty of clinical pharmacists. Finally, we asked the BHP to engage in measurement-based care and provide that information and behavioral recommendations to the PCP, which allowed the PCP to understand the impact/intensity of the patient's pain and develop a basic understanding of CBT-CP approach. Preliminary feedback using follow-up qualitative interviews with 2 PCPs and 1 BHP on this innovative, strategic approach revealed that the PCPs reported an improved understanding of the biopsychosocial model, work satisfaction, and confidence in caring for patients with chronic pain.

### Team Huddles

PC is critical to suicide prevention, as a majority of patients who die by suicide were seen in PC in the month prior to suicide (33). The American National Action Alliance for Suicide has developed clinical practice guidelines (CPGs) to assist PCPs in providing evidence-based care for patients at-risk for suicide (34). A team-based, biopsychosocial approach is particularly important in applying the first step of the CPGs, determining that a patient is at-risk for suicide, as PC team members can help identify various biological (e.g., chronic pain), psychological (e.g., depressive symptoms), and/or social (e.g., job loss) risk factors for suicide. However, consistent provision of care that is concordant with CPGs for suicide prevention remains a critical concern (13, 35, 36). This may be due in part to ineffective formats for educating providers, as didactic education and passive dissemination do not sufficiently improve knowledge of and adherence to CPGs (13). Another potential barrier is that patient openness to sharing suicide-related information is influenced by how PC team members ask risk assessment questions and facilitate rapport (37). Therefore, efforts to educate providers on suicide prevention CPGs need to attend to both approach and content; that is, delivering highly adherent, evidence-based care in a patient-centered way. This is a challenge for healthcare professionals with little or ineffective training on this topic (38).

Team huddles offer an opportunity to strategically address these challenges. Several key functions of team huddles can help to improve patient care, including reviewing and planning for upcoming patients; improving team communication and coordination efforts; and increasing shared awareness of team members' roles and tasks (39). Research supports these benefits of huddles, such that PC team members who attended huddles reported higher scores on teamwork, decision-making, and psychological safety within the team compared to those who did not attend huddles (39). Thus, if used consistently by all team members, huddles can serve as a powerful tool to improve team functioning and patient care. In practice, however, strategic planning is helpful to facilitate optimal interprofessional education in huddles and overcome barriers such as lack of regular attendance (7, 39).

Our team has developed Team Education for Adopting Change in Healthcare (TEACH), a series of four brief team meetings that mimic a huddle format, to improve suicide prevention practices within integrated PC. All members of



**TABLE 1** | Goals of four meetings in the TEACH intervention.

Meeting #	Type	Content of meeting
1	Overview	<ul style="list-style-type: none"> <li>• Orientation to TEACH meeting format and goals</li> <li>• Discuss role of entire primary care team and team process as review the clinical practice guidelines for suicide</li> </ul>
2	Team briefing part 1	<ul style="list-style-type: none"> <li>• Identify roles of team and how communication works between providers when encountering different types of patients, who report suicidal ideation</li> </ul>
3	Team briefing part 2	<ul style="list-style-type: none"> <li>• Simulate delivering clinical practice guideline-concordant care at an upcoming at-risk patient's appointment</li> </ul>
4	De-briefing	<ul style="list-style-type: none"> <li>• Review how the process went with a previous at-risk patient and problem solve issues</li> </ul>

the PC team are involved in TEACH meetings, including the embedded BHP. TEACH incorporates interactive education with experiential learning components using a simulation strategy (40) to help improve knowledge of and familiarity with CPGs as well as team briefing and debriefing, which has been found in prior research to improve team processes (41–43). As shown in **Table 1**, biopsychosocial care is a primary educational objective that is reinforced during each meeting by reviewing which team members should assess or provide treatment for biomedical (e.g., PCP prescribes medication), psychological (e.g., BHP develops safety plan with the patient), and social (e.g., social worker connects patient to housing resources) concerns that may contribute to suicide risk. Other educational objectives are to improve team knowledge of the CPGs and team processes to ensure high quality delivery. To increase fidelity to and the impact of TEACH, the four team meetings are dispersed across 12 weeks and occur within the natural work environment (including virtual care if applicable) (44). TEACH is currently being piloted within 2 VHA integrated PC clinics, with 4 teams receiving TEACH and 4 teams continuing to receive standard suicide prevention support. Data will be collected from team members, and the electronic medical record to preliminarily examine feasibility and acceptability.

## Conjoint Appointments

Cardiovascular diseases (CVDs) are among the most common (~40–60%) and costly health concerns among United States military Veterans (45, 46), and the monitoring of and prevention efforts for CVDs tends to occur in PC settings (47). CVDs are influenced by a number of behavioral factors, such as drinking alcohol at risky levels (48–51) and behaviors which are affected by psychosocial factors (e.g., low motivation to change behavior). PCPs who feel uncomfortable addressing the psychosocial aspects of CVD are less likely to fully address biopsychosocial concerns like risky drinking (52). Many PCPs (68%) do not have prior experience with motivational interventions and

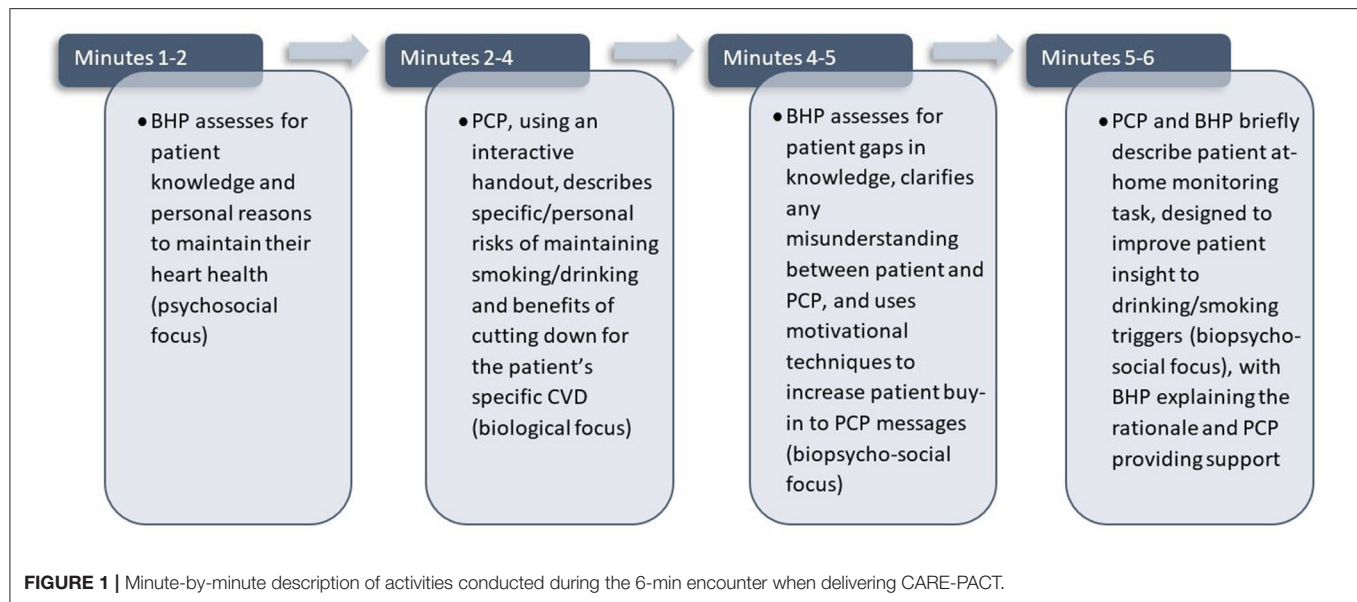
report lower confidence than BHPs at strengthening patient motivation (53). On the other hand, a BHP alone may not be trained/able to address all the biological aspects of smoking/drinking, particularly when they occur in the context of comorbid and complex health conditions such as CVD (54). Medical comorbidities can be important motivators for patients who engage in risky alcohol or tobacco use (55). Thus, if BHPs are not routinely discussing the connection between health and behavior, there may be missed opportunities to inspire change.

Research has found that observing/shadowing providers in action improves a learner's ability to provide comprehensive, biopsychosocial care in the future (56). Experiential learning also improves interprofessional awareness and team functioning, as providers gain appreciation for their colleagues' expertise (57), and solidifies non-experience driven learning. Thus, we have developed and are piloting a *conjoint appointment* protocol called Cardiovascular disease and substance Risk Education—Patient Aligned Care Team (CARE-PACT) where a PCP and BHP meet dually with a patient to discuss the patient's smoking/risky drinking within the context of their diagnosed CVD. In bringing together providers with expertise in differing areas of the biopsychosocial spectrum, conjoint appointments are an excellent approach for patients who have mental/behavioral health concerns related to medical concerns (20, 58, 59) and also provide an opportunity for providers to demonstrate and acquire biopsychosocial skills through collaboration with providers from a different training background.

In CARE-PACT, the PCP and BHP each have specific roles and content areas to share with the patient during a brief 5–7 min encounter. As outlined within **Figure 1**, the BHP uses motivational interviewing approaches (60) to evaluate patient motivational factors, assess for understanding, and increase patient buy in, thus providing the opportunity for PCPs to learn. The PCP addresses the patient's personal risks and potential benefits of changing smoking/drinking given their specific CVD, thus providing the opportunity for the BHP to learn more about biological complexities associated with smoking/drinking. The conjoint appointment ends with the patient having the option to follow-up with the BHP. CARE-PACT is currently being piloted in an open trial in two VHA PC clinics, where 4 PCPs and their embedded BHP will deliver CARE-PACT to 15 PC patients with cardiovascular disease who engage in at-risk alcohol use/smoking. Following the intervention, patients and providers will provide feedback on acceptability and feasibility.

## DISCUSSION

These three protocols demonstrate how team-based care activities with empirical support for improving direct patient care, such as SMAs (30, 31), can be strategically structured to provide opportunities for biopsychosocial education of PC team members. Although the specific protocols shared in this article are still undergoing formal evaluation as venues for interprofessional education, the strategic education provided within these team-based care activities has the potential to



improve not only provider understanding and utilization of patient-centered biopsychosocial approaches to care, but also teamwork processes in the relational aspects of care delivery [e.g., shared mental models; (17)] by giving team members additional opportunities to collaborate. These team-based care activities also pragmatically leverage real-world clinical care activities to bridge conceptual gaps that can only be addressed through interdisciplinary collaboration. Observations from this initial pilot work suggest that these experiences are perceived as rewarding by providers and may also help decrease provider burnout by offering variety in daily activities. However, future research is needed to fully understand the educational value of these activities on their own or in comparison to one another as well as continue to identify the benefits of these activities to patient care. Therefore, it is difficult to recommend one approach over another at this time.

All of these case examples were designed to be delivered with all team members being in-person, but the advent of the COVID-19 pandemic has caused a shift toward greater utilization of virtual formats for patients and employees. This shift is likely to remain beyond the current pandemic, as telehealth and telework offer advantages in overcoming scheduling issues as well as sustainability. Existing research suggests that virtual interactive learning methods can still be effective and result in similar educational gains as in-person (61, 62); however, future research would need to determine if other strategies need to be considered to achieve success in provider education via virtual platforms.

Similarly, there have been advances in understanding how to navigate the ethical considerations associated with an integrated team approach to patient care (63, 64); however, continued attention to the ethical considerations within these contexts is also necessary.

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# Anti-racism Training Using the Biopsychosocial Model: Frederick Douglas' Earthquake, Whirlwind, Storm and Fire

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Rochester, New York is home to George Engel and the Biopsychosocial (BPS) model. Rochester was also home to Fredrick Douglas and a stop on the Underground Railroad. More recently, Rochester, New York is also where Daniel Prude died at the hands of the police. In this article, we discuss how our department of family medicine has incorporated race and racism into the BPS model and how we have used it to help primary care trainees become more effective in their work with Black Indigenous and people of color (BIPOC) patients.

**Keywords:** biopsychosocial approach, racism, medical education, communication, physician-patient relations, community advocacy

## INTRODUCTION

The University of Rochester is across the street from the grave sites of two historical leaders for social justice in the United States: Frederick Douglass (1) and Susan B. Anthony (2, 3). Both were internationally renowned change agents for the disenfranchised. Douglass was an abolitionist and talented orator who not only spoke out against slavery, but also risked his life to lead Rochester's hub for the Underground Railroad that passed through his Rochester farmhouse. Susan B. Anthony was a leader in the women's suffrage movement, an anti-slavery activist and a lifelong friend of Douglas.

The University of Rochester, was once a professional home for George Engel and Harriet A. Washington. In 1977, Dr. Engel proposed the need for medicine to shift from an exclusive biomedical focus to a new model of care that integrates psychosocial elements of people's lives—A Biopsychosocial (BPS) model (4). The BPS model takes into account the patient, the social context in which they live and the clinician's role and the health care system in which they operate. Almost 30 years later, Washington won the National Book Critics Circle Award (5) for *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*, a historical account of the racist travesties of medical experimentation on African Americans (6).

More recently, Rochester is known for the 2020 death of Daniel Prude (7). Mr. Prude suffered from mental illness. He was seen at the University of Rochester emergency department for self-injurious behavior and released. He died after being physically restrained by police officers, the cause of death was determined by the coroner to be homicide (8). In response to the events surrounding his death, medical students at the University of Rochester indicated that "Not only do our current models of healthcare leave gaping holes for individuals such as Daniel Prude to fall through, but they do so in manners which are fraught with racism (9)".

The BPS model has transformed how medical educators teach trainees how to talk with patients (10, 11), but does not directly address the role of racism in the lives of Black, Indigenous and people of color (BIPOC) patients. Rather than asking a series of closed ended or narrow questions designed to quickly make a diagnosis, George Engel urged clinicians to listen while patients told their story. Engel insisted that more often than not, patients' uninterrupted history would provide key, psychosocial contextual factors that would enable the clinician to not only understand their patients' illness within context, but also provide guidance for more effectively treating the patient. Yet racism was not part of Engel's model.

To better understand the role of racism, we turn to the words of Frederick Douglass. Using his words to build a framework for incorporating racism into the BPS model for teaching and praxis:

*"For it is not light that is needed, but fire; it is not the gentle shower, but thunder. We need the storm, the whirlwind, and the earthquake".*

- Frederick Douglass during a Fourth of July celebration in Rochester, NY in 1852 (12).

## DISCUSSION

### The Thunder

Many White trainees have learned to be "color blind" and to treat people the same (13, 14). White culture following the Civil Rights legislation has tended to minimize the role of racism on the lives of BIPOC often resulting in White denial of everyday racism and much less one's own implicit racial biases or one's own privilege based on White skin color (15–18). The stream of viral videos documenting violence toward BIPOC has helped weaken the White taboo about discussing racism. It has created an opening for dialogue, if not the thunder and lightning bolt,

regarding the profound impact it has on the lives of BIPOC and on the psyches of Whites (19).

White denial of racism can be addressed through activities such as implicit bias training, self-reflection and creating psychological safety in which trainees can share their own experiences with discrimination, stigmatization and marginalization (20). These discussions are not intended to equate experiences, but rather to sensitize trainees to their own affective experiences. Having skilled, racially diverse facilitators can increase psychological safety, particularly when facilitators can acknowledge and role model, sharing what they have learned about their own blind spots and implicit biases. This "gentle shower" prepares trainees for the thunder of BIPOC patient experiences. Recognition of racism and privilege can sensitize trainees to the role of the micro-dynamics of power within the patient-clinician relationship in addition to the macro dynamics of power and privilege in society including how it shapes politics, structural social disadvantage and constrained opportunities and privilege in education, law, employment and health care.

### The Storm

For trainees who have not talked about race or racism with patients, it may feel like entering a storm of emotions. Patients may recount trauma, anger, sadness and despair related to racism whether structural, interpersonal, or even internalized. Like storms, emotions can ebb and surge unexpectedly. Trainees may feel they are losing control of the visit. And trainees accustomed to intervening will struggle to listen and witness patients' experiences without attempting to rationalize them. Trainees often need reassurance that listening and witnessing is more powerful by itself. Engel taught his trainees that careful listening offers insights into the patient's biopsychosocial context. When a racism lens is added, trainees learn how race affects the

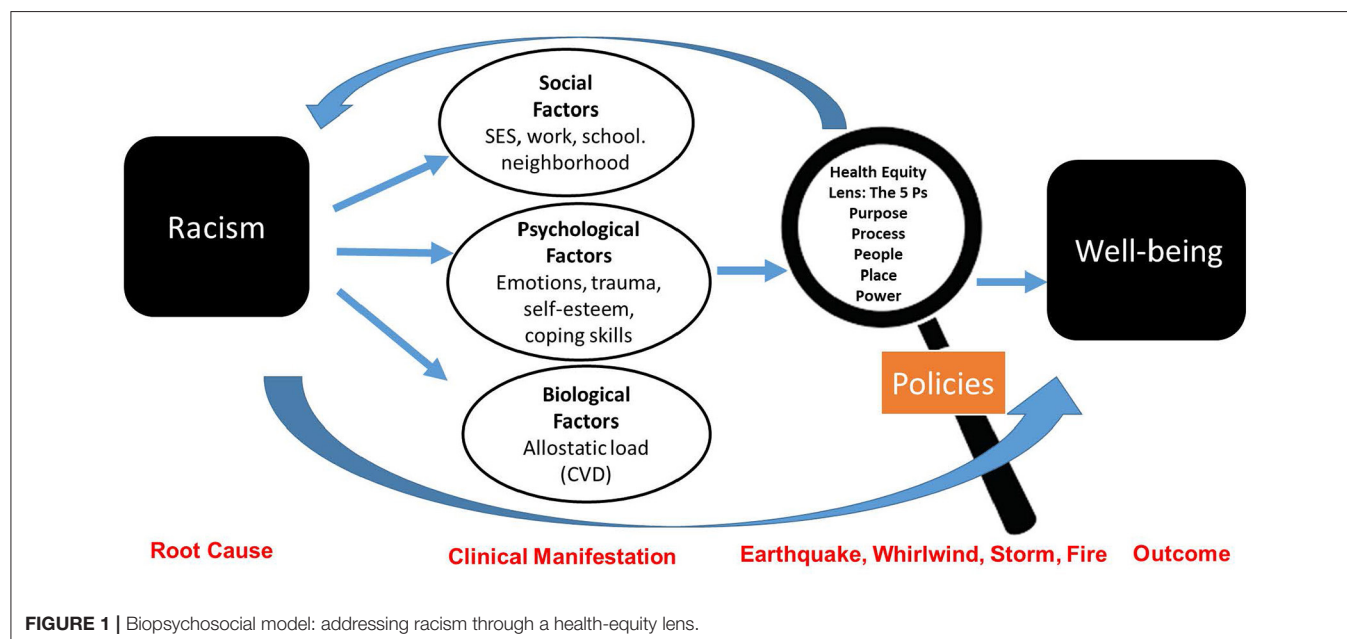


FIGURE 1 | Biopsychosocial model: addressing racism through a health-equity lens.

life of the patient, while providing an informal lesson in racism based on mini-ethnography (21).

## The Whirlwind

Some trainees will struggle with the whirlwind of their own emotions. Some will need coaching in avoiding premature or false re-assurance. Others will need to be coached in channeling their own righteous anger. Others may need to seek out counseling for themselves when these experiences trigger their own past traumas and feelings of being marginalized or degraded. This whirlwind of emotions becomes an opportunity to teach trainees mindfulness related to the emotions expressed by patients, but most importantly acknowledging their own emotions and how to effectively manage them during patient visits (22).

## The Earthquake

Many trainees may experience an earthquake that shakes up their own assumptions about racism in the world, its impact on their own privilege and its pernicious impact on their own implicit attitudes. Skilled facilitation of diverse anti-racism groups in which members can be vulnerable provide space for members to reflect on racism and its impact on themselves and colleagues. Time devoted to sharing of experiences and reflections can create added safety.

## The Fire

Earthquakes and whirlwinds are often accompanied by fire. It was fire that Douglas was seeking to ignite among his White audiences, notably his “What to the Slave Is the Fourth of July” speech in Rochester in 1852 (23). Douglas hoped that this internal fire would inspire his audience to take up action against racism and its manifestation in chattel slavery. Similarly, many trainees will experience a fire to act. We have found this can be channeled through advocacy. Advocacy can be patient-based. This can mean connecting patients with resources to address social determinants of health (24). It can also mean advocating for patients within the health care system while supporting the patients’ voice (25). It also means partnering with organizations to address structural racism (26). Our department sponsors a monthly seminar that includes documentaries, e.g., the Rochester race riot and speakers who address ways that trainees can take action. These sessions can help trainees find opportunities for advocacy, whether serving on antiracism departmental or medical school committees, supporting and empowering minoritized group organizations, or working on health equity, quality improvement initiatives.

The tragic death of Daniel Prude offers a powerful and heartrending story for discussion of how structural, interpersonal and internalized racism affects patients. According to press accounts (27), Mr. Prude’s life was all too familiar. He was a father of five children who lived in Chicago where he grew up in a public housing complex. Two of his siblings died in tragic incidents that traumatized him. As an adult, Mr. Prude worked in warehouses and factories on the Southwest side of Chicago, while helping other people in his neighborhood

get jobs. In 2018, a nephew of Mr. Prude committed suicide by gunshot in the home they shared. After this trauma, Mr. Prude reportedly, increasingly used phencyclidine (PCP) with resulting erratic behavior. He took his final train trip to Rochester, NY after his sister told him to leave her home due to his growing paranoia. Once in Rochester, his brother took him to the hospital for erratic behavior where he calmed down. He was subsequently released, only to run away from his brother’s home before dying, hooded, naked, and restrained by police, who reportedly applied pressure under his jaw to a nerve, pinning him to the street. The narrative and 11-min police video painfully underscore how structural, interpersonal, and internalized racism interacted with the psychosocial context of Daniel Prude’s life—ultimately ending it with a half dozen police in witness.

Medical trainees should be encouraged to “light fires” and engage in civic action in order to prevent and dismantle racist policies that hinder the well-being of their patients. The intensity in engagement can range from providing data on the impact of policies on health to policy leaders, to collaborating with community-organizations to enact policy changes. All engagement should center on health equity.

## BPS+R Model

We propose the BPS+R model that incorporates the 5Ps Health Equity and Empowerment Lens (26). The 5Ps (purpose, people, place, process and power) can be used for both institutional and civic engagement outside the clinical encounter. The 5 Ps are a set of guiding principles and reflective questions to evaluate whether policies have a positive impact on well-being and achieve health equity **Figure 1**. For example, racialized segregation created by federal housing policies has had a lasting impact not only on where a person lives, but also their access to employment and exposure to health hazards (e.g., pollution) (28). These downstream inequities manifest in a person’s biological, psychological and social health. Therefore, use of the BPS model alone will be ineffective in treating the root cause of poor health, racism. Treatment can be achieved through changes in policies and interpersonal work. These principles have been endorsed as a training tool by several county health departments to help develop more racially equitable policies and programs (29–32).

The 5Ps can be used to assess whether any proposed changes in policy further exacerbate racism or work toward health equity. Consider Mr. Thomas, a (fictional) 55 yr. old man with uncontrolled hypertension, who lives alone in his childhood home. The home is paid for, but he has to work two jobs to keep up with the property taxes and amenities. The neighborhood has changed since he was a child. Gentrification and poverty have changed the social and physical composition of the neighborhood. He cannot afford, nor does he want to leave the home his parents struggled to pay for in the 1970s. **Table 1** outlines a composite example of how trainees can treat the root cause of Mr. Thomas’ uncontrolled blood pressure. While it may appear that treating his uncontrolled blood pressure with medication will solve the issue, a deeper reflection reveals

**TABLE 1** | Example of how trainees can treat the root cause of uncontrolled blood pressure.

	<b>Issue</b>	<b>Clinical Action: BPS Model Tx only</b>	<b>Institutional Action: BPS Model Tx +QI HE</b>	<b>Civic Action: BPS Model Tx + 5Ps HE lens</b>
Biological	Mr. Thomas' blood pressure has been uncontrolled for over a year.	Rx: HTN meds and recommend that he monitor his blood pressure at home.	Ask health care leadership to purchase a set of digital home blood pressure monitors (HBPM) that patients like Mr. Thomas can borrow for free as they work to bring their BP in control. <b>Purpose:</b> To eliminate the impact of racism on blood pressure control. <b>Place:</b> How are blood pressure control tools distributed amongst patients within your practice? <b>Processes:</b> What institutional policies contribute to Mr. Thomas' inequities? Is there support for the patient without broadband access that the patient would like to participate in for HBPM? <b>Power:</b> How have you helped to shift power dynamics to better integrate voices and priorities of Mr. Thomas?	Donate time and or financial resources to local a community-based organization that is working on the issue of walkable sidewalks and ask your colleagues to do the same. <b>Purpose:</b> To eliminate the impact of racism on built neighborhood. <b>People:</b> Ensure the policy action will positively affect your patients. <b>Place:</b> To make certain public resources are being equitably distributed geographically. <b>Processes:</b> Check and re-check whether the policy will inadvertently contribute to Mr. Thomas' inequities. <b>Power:</b> Confirm you have helped shift the power dynamics to better integrate voices and priorities of Mr. Thomas.

the contrary. A lack of institutional resources and racialized gentrification are what need to be treated.

Mr. Thomas is a composite of patients we worked with; real-world Mr. Thomas' are not difficult to find. Therefore, the BPS+R model is critical to reducing health disparities. Without it, trainees lack the sociocultural context that explains the circumstances that have led to the health outcomes and health behaviors of many BIPOC patients.

## Comparison to Other Anti-racism Training Models

The BPS-R is unique in several respects. First, it is grounded in the influential BPS model (33), while adding the critical lens of race. Second, the model integrates existing approaches to antiracism training. A realist review of anti-racist pedagogy in health professional education distinguished four pedagogical approaches: dialogue across social groups, deconstructing power and privilege, trainee transformation and application to practice (34). Our model integrates these four approaches. It adds the race lens to promote dialogue across race. It deconstructs power and privilege using the 5 P's. It promotes trainee transformation through the mini-ethnography of the BPS combined with discussion and reflection.

## LIMITATIONS

There are a few limitations to our proposed model we would like to note. First, we recognize that broader structural changes and training will be required to enhance the utility of the BPS-R model. Anti-racism training is new to medical education. Similar to other existing models, there is a need for research to assess the impact of BPS-R training on trainees, patients, and communities (35). Future research will need to delineate the specific strengths and weaknesses of the BPS-R and other antiracism training models. Second, the 5Ps is a pragmatic, reflective model that trainees can use as a lens to engage in

civic action and it is not a panacea for eliminating the impact of racism on patients. Nonetheless, there is precedent in our community for health professionals successfully engaging in civic action to drive health policy change (36–39). The *Rochester Lead Law* (38, 40–42) is an example of a public policy that was led by members of the community (including health care professionals), which has helped to reduce lead poisonings and focus resources to our most economically challenged neighborhoods. This level of civic engagement is not trivial and requires personal will, courage, and collective power (43). But, as Hardeman et al. note, clinicians and researchers wield power, privilege, and responsibility for dismantling structural racism (44).

## Lessons

Our department has incorporated the role of racism into the curriculum in various ways over several decades, often through community medicine and through the biopsychosocial curriculum. Our experiences suggest that incorporating anti-racism into the BPS model takes time. Residents vary in their willingness to acknowledge their own implicit biases and White privilege. Ensuring consistency in racial diversity among trainees has been a challenge. Peers are an important source of learning for residents (45), and lack of diversity fosters color blindness.

Similarly, leadership matters. Both our medical school and departmental leaders have made public commitments to advancing racial equity and inclusion and implementing anti-racism efforts. Leaders can help keep anti-racism in the spotlight and foster a culture of learning and reflecting. Applying an antiracism lens to the BPS model is a reasonable place to start.

## DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.



## AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct and intellectual contribution to the work, and approved it for publication.

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# Development and User Experiences of a Biopsychosocial Interprofessional Online Course on Persistent Somatic Symptoms

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**Background:** Communication between healthcare providers and patients with persistent somatic symptoms (PSS) is frequently hampered by mutual misunderstanding and dissatisfaction.

**Methods:** We developed an online, interprofessional course to teach healthcare providers the knowledge, skills, and attitude they need to diagnose and treat PSS in a patient-centered manner based on the biopsychosocial model. The course consisted of six modules of 45–60 min. Each module contained different types of assignments, based on six cases: videos, discussion boards, reading assignments, polls, and quizzes. For this study, we included (1) medical residents, following the course as part of their residency training, and (2) healthcare providers (general practitioners, medical specialists, physiotherapists, nurses, and psychologists), following the course as continuing vocational training. Throughout the course, participants were asked to fill out online surveys, enquiring about their learning gains and satisfaction with the course.

**Results:** The biopsychosocial approach was integrated across the modules and taught health care workers about recent insights on biological, psychological and social aspects of PSS. In total, 801 participants with a wide variety in clinical experience started the course; the largest groups of professionals were general practitioners ( $N = 400$ ), physiotherapists ( $N = 124$ ) and mental healthcare workers ( $N = 53$ ). At the start of the course, 22% of the participants rated their level of knowledge on PSS as adequate. At the end of the course, 359 participants completed the evaluation questionnaires. Of this group, 81% rated their level of knowledge on PSS as adequate and 86% felt that following the course increased their competencies in communicating with patients with PSS ( $N = 359$ ). On a scale from 1 to 10, participants gave the course a mean grade of 7.8 points. Accordingly, 85% stated that they would recommend the course to a colleague.

**Conclusion:** Our course developed in a co-design process involving multiple stakeholders can be implemented, is being used, and is positively evaluated by professionals across a variety of health care settings.

**Keywords:** persistent somatic symptoms, interdisciplinary, eHealth, online course, education, biopsychosocial, somatic symptom disorder

## INTRODUCTION

A substantial proportion of physical symptoms cannot be (fully) explained by a medical disease. This varies from ~20–35% in primary care to 30–50% in secondary care (1–4). Even though most physical symptoms are self-limiting, 10–30% of symptoms persist after a year, causing considerable suffering and disability (5). Those persisting somatic symptoms (PSS) are associated with increased use of healthcare resources and their medical costs rank among the highest of all patient groups (6). This is partly due to repeated referrals and investigations, which are often unhelpful and sometimes even cause iatrogenic damage (7).

PSS result from the complex interplay of biomedical, psychological and/or social (biopsychosocial) factors. This multifactorial etiology complicates the deduction of a clear diagnostic and treatment rationale used by all different types of health care providers (8).

Many healthcare providers perceive patients with PSS as “heartsink” or “difficult” (9). Many patients with PSS feel like they are not being taken seriously by healthcare providers (10). Misconceptions are found on both sides, hampering effective treatment and recovery of patients with PSS (11). For example, the labels that doctors use to describe PSS often lead patients to believe that the doctor is suggesting they are “putting on” or “imagining” their symptoms, or that they are “mad” (12). In addition, professionals from different disciplines use their own labels and concepts for PSS, often emphasizing either biomedical or psychosocial factors, leading to an inconsistent and suboptimal approach of patients with PSS. Also, doctors often feel pressurized and uncomfortable, because they feel patients demand (unnecessary) somatic interventions. However, research shows that it is mostly doctors proposing somatic interventions, not patients. If anything, patients with PSS seek for emotional support and reassurance (13). Clearing up these misconceptions calls for better interpersonal communication, a more patient-centered biopsychosocial approach across professionals from different disciplines and knowledge about treatment options. In recent years, a paradigm shift has emerged to organize care from a patient instead of a provider perspective. This means providing care that is respectful of and responsive to the needs, values, and preferences of individual patients, and actively involving patients in clinical decisions (14). Patient-centered care has many benefits: it improves job satisfaction among healthcare providers, patient wellbeing, treatment compliance, and health outcomes without increased use of healthcare resources (15). The treatment of PSS often involves somatic and psychosocial health care providers and requires a biopsychosocial approach and common interdisciplinary language.

To promote patient-centered care for patients with PSS, we aimed to develop an online course, teaching healthcare professionals from various disciplines the knowledge, skills, and attitude they need to adequately diagnose and treat PSS, based on a biopsychosocial perspective. Online learning (“e-learning”) is an innovative form of education, which is appreciated for its flexibility, convenience, and self-controlled learning pace (16). The use of different types of media and interactive tools increases motivation and promotes practically applied learning,

resulting in more efficient learning experiences (17). In this paper, we describe the development of this course, healthcare provider satisfaction with the course, and self-reported effects on knowledge, skills, and attitude.

## METHODS

### Course Development

PSS experts, educational experts, healthcare professionals from various disciplines (i.e., general practice, clinical psychology, psychiatry, physiotherapy, and various medical specialties), and a patient representative were involved in the development of the course. As a first step, workshops were organized to define the aim of the course, the intended target audience, relevant themes, and learning goals. Subsequently, we established a fixed structure for all course modules and decided on types of assignments that were to be used. Six cases were created for these assignments (see **Box 1**). Four of these cases were based on prototypical PSS patients, according to a focus group study amongst Dutch general practitioners (GPs) (the passive PSS patient, the anxious PSS patient, the distressed PSS patient, and the unhappy PSS patient) (18); The remaining two were created for a specific learning goal. Then, all of the individual assignments were drafted, which included filming of interviews with experienced clinicians, recording “screencasts” (2–3 min explanatory videos), and filming re-enacted consultations with actors. The stakeholders were asked to give feedback on this first version of the course. Finally, a pilot was organized with 64 experienced GPs. Divided into two groups, they completed three course modules (1, 3, and 5 or 2, 4, and 6). Afterwards, structured focus group discussions were organized to gather qualitative feedback which was used to fine-tune the course in terms of form (structure, length of the modules, teaching methods) and content (topics, relevancy, level). The course was developed and piloted in the Dutch language and subsequently translated into English and German.

### Course Structure and Content

The aim of the course was to teach healthcare providers how to diagnose and treat PSS in a patient-centered manner. In order to facilitate interprofessional collaboration and communication between different types of healthcare providers using the biopsychosocial model as a basis, the course was designed for all healthcare providers involved in the care of patients with PSS, including GPs, medical specialists (internists, gastroenterologists, rheumatologists, gynecologists, neurologists, psychiatrists, rehabilitation specialists, and occupational physicians), physiotherapists, nurses, psychologists, and other mental healthcare workers.

### Participants

We recruited participants for this study in two ways. First, the online course was implemented in the training of medical residents from various specialties in the University Medical Centers of Groningen, Nijmegen and Amsterdam, the Netherlands. Second, the course was offered to various



**BOX 1 |** Cases of patients with PSS used in assignments throughout the course.**Case 1**

Forty one-year-old single mother of two visits her general practitioner (GP), because she is increasingly bothered by gastrointestinal complaints. She was diagnosed with irritable bowel syndrome 10 years ago, which runs in her family. The symptoms had been manageable for years, but recently she has been frequently experiencing diarrhea, flatulence, bloating, and fatigue. The patient feels very ashamed of these symptoms. She has no idea why the symptoms have worsened and does not know what to do about it.

**Case 2**

Since she has had the flu 6 months ago, a 19-year-old psychology student has been experiencing ongoing fatigue, headache, neck pain, and trouble concentrating. She regularly takes naps during the day, because she cannot stay awake. She is no longer able to play handball or study. She worries that her symptoms will not go away.

**Case 3**

A 43-year-old IT-specialist visits his GP, because he has been experiencing chest pains and palpitations for 2 weeks. Five months ago, he visited the emergency department with acute chest pain, which was classified as atypical, non-cardiac chest pain. The patient and his wife are very worried and insist they would like to be referred to a cardiologist. Two years ago, a friend died of a heart attack and the patient fears this might happen to him as well.

**Case 4**

Four months ago, a 32-year-old lawyer suffered from sudden and severe vertigo, nausea and vomiting. She was diagnosed with vestibular neuritis. The patient now visits her GP, because she keeps feeling dizzy and unsteady. She is also very tired and sometimes feels like she is “not quite there”. The patient feels stressed out, because the symptoms interfere with her demanding job.

**Case 5**

A 51-year-old man with type 2 diabetes has been suffering from generalized, chronic pain for 3 years. A rheumatologist could not find a medical explanation for the symptoms. The patient now visits his GP, because the pain in his hands and knees has increased. This has led him to cease his hobbies: fishing and playing cards with friends. The patient seems down. There is not much he enjoys in life.

groups of Dutch healthcare providers as continuing vocational training, for which they had to pay € 100. In the Netherlands, registered healthcare providers are obliged to take a certain amount of accredited courses. Our course was accredited for GPs, medical specialists, physiotherapists, nurses, and psychologists. In order to recruit participants for this group, we promoted the course through a website (<https://Grip.Health/Pages/Elearning>), social media (twitter, linkedin), short articles in Dutch medical journals, and local/national meetings for healthcare providers. To be awarded accreditation points, these healthcare providers had to finish all of the course modules. Participants were recruited between September 2017 and June 2021.

## Evaluation

Throughout the course, participants were asked to fill out custom designed, integrated online surveys. These surveys were offered (1) before the start of the course (i.e., before the first course module), (2) after each of the course modules, and (3) after finishing the course (i.e., after the final course module).

### Participant Characteristics

The survey before the start of the course contained questions on participants' sex, age, profession, and years of clinical experience.

### Self-Reported Knowledge, Skills, and Attitude

The surveys before the start and after the end of the course contained general questions on participants' attitude toward and knowledge of PSS. The surveys at the end of the various course modules evaluated (improvements in) knowledge, skills, and attitude with regard to the specific themes of the module (i.e., whether learning goals were met). Items from all these surveys were phrased as statements with a five-point likert

scale (fully disagree / disagree / neither disagree, nor agree / agree / fully agree). For the variables assessing learning goals of the individual modules, responses “agree” (4) and “fully agree” (5) were combined.

### Satisfaction

The evaluative survey at the end of the course assessed participants' satisfaction with the course. Participants were asked to grade the course on a scale from 1 to 10. In the Netherlands this is a common scale in education, with six referring to pass, eight to good, and 10 to excellent. In addition, they were asked whether they would recommend the course to a colleague and whether the course content was directly applicable in their daily practice. These items were phrased as statements with a five-point Likert scale (fully disagree / disagree / neither disagree, nor agree / agree / fully agree). For these variables, responses “agree” (4) and “fully agree” (5) were combined.

## RESULTS

### Development of the Course Modules

The workshop identified six themes with specific learning goals. The Canadian Medical Education Directives for Specialists (CanMEDS) framework (19) was used to link these themes (modules) and learning goals to relevant competencies for medical professionals. These CanMEDS competencies were then translated into six course modules (see **Table 1**). Each module had the exact same structure. It started with the learning goals of the module, followed by 6 to 15 short assignments (videos, discussion boards, reading assignments, polls, and quizzes). All modules ended with a take-home-message, an evaluative survey and a “further reading” segment.

**TABLE 1** | Learning goals per course module with relevant CanMEDS competencies.

Module		Learning Goals	CanMEDS competency <sup>a</sup>						
		<i>After following this module, the participant will:</i>	a	b	c	d	e	f	g
1	Introduction	<ul style="list-style-type: none"> <li>Be more aware of their attitude toward patients with PSS</li> <li>Have gained insight into 10 common misconceptions about PSS</li> </ul>	.	.	.	.	.	.	✓
2	Basic knowledge	<ul style="list-style-type: none"> <li>Have gained basic knowledge on the terminology, prevalence, prognosis, and etiology of PSS</li> </ul>	✓	.	.	.	.	✓	✓
3	Assessment	<ul style="list-style-type: none"> <li>Be able to make informed decisions on diagnostic testing, avoiding unnecessary procedures</li> <li>Know how to minimize the chance of misdiagnosis</li> <li>Be able to recognize and explore the 5 symptom dimensions (physical, cognitive, emotional, behavioral, and social)</li> <li>Be able to recognize psychiatric comorbidity</li> </ul>	✓	.	.	.	✓	✓	.
4	Consultation	<ul style="list-style-type: none"> <li>Be able to recognize signs that a patient feels unheard</li> <li>Know how to use physical examination to effectively reassure a patient</li> <li>Be able to explain the working diagnosis “PSS” to a patient</li> <li>Be able to recognize and prevent a common negative interaction pattern</li> </ul>	✓	✓	.	.	✓	.	✓
5	Treatment in primary care	<ul style="list-style-type: none"> <li>Be able to assess the severity of PSS</li> <li>Know methods to motivate patients for behavior change</li> <li>Be able to set treatment goals together with a patient and monitor progress</li> </ul>	✓	✓	✓	✓	.	.	.
6	Collaboration	<ul style="list-style-type: none"> <li>Know how to improve communication and collaboration with other health care providers</li> <li>Know which are key elements in a good (referral) letter</li> <li>Know when and how to refer a patients with PSS to mental healthcare</li> </ul>	✓	✓	✓	✓	.	.	✓

<sup>a</sup>Canadian Medical Education Directives for Specialists (CanMEDS) is a framework, aimed to improve care by enhancing physician training, including the following competencies/roles (19) a, medical expert; b, communicator; c, collaborator; d, leader; e, health advocate; f, scholar; g, professional.

**TABLE 2** | General characteristics of online PSS course participants (*N* = 801).

Variable	
Male sex, <i>n</i> (%)	213 (26.6%)
Age in years, median (IQR)	33 (29–49)
Clinical experience in years, median (IQR)	6 (3–20)
Profession, including residents and trainees, <i>n</i> (%)	
General practitioner	400 (49.9%)
Physiotherapist	124 (15.5%)
Psychologist or other mental health worker	43 (5.4%)
Psychiatrist	10 (1.2%)
Internist, rheumatologist, gastroenterologist	34 (4.2%)
Rehabilitation specialist	15 (1.9%)
Neurologist	6 (0.7%)
Other	98 (12.2%)
Unknown (not reported)	47 (5.9%)

The biopsychosocial approach was integrated across the modules and taught health care workers about recent insights on biological, psychological and social aspects of PSS. In

module 1, the main theme was correcting the misconceptions related to PSS being a problem (only) with a psychological origin. Module 2 introduced the etiology of PSS, discussing the contribution of biological, psychological and social factors. Module 3 included information on diagnoses of somatic and psychiatric diseases, and on how to explore physical, cognitive, emotional, behavioral and social symptom dimensions. Module 4 focused on relational aspects and communication during consultations, with exercises about biopsychosocial explanations for PSS. In module 5, treatment was introduced, with information on optimal communication for motivation of patients. Finally, module 6 focused on interprofessional collaboration and role differentiation, how to work as a team, and educated participants on how to communicate with healthcare professionals from different disciplines and when to refer a patient to mental health care.

## Participants

Before the start of the course, 801 participants filled out the general survey (see **Table 2**). Most of these were GPs, physiotherapists and psychologists or other mental health care providers (including residents and trainees). Years of clinical experience ranged from 0 to 45 and a median

**TABLE 3 |** Self-rated knowledge, skills, and attitude on PSS after each of the course modules.

Learning gains after course module	Module	(Fully) agree	N
Increased awareness of attitude toward PSS	1	73%	680
Changed attitude toward PSS	1	33%	680
Knowledge on terminology adequate	2	80%	516
Knowledge on prevalence and prognosis adequate	2	79%	516
Knowledge on etiology adequate	2	83%	516
Increased awareness of consequences diagnostic procedures and referral	3	74%	447
Better able to recognize and explore symptom dimensions	3	72%	447
Improved ability to recognize when patient feels unheard	4	80%	400
Knows how to explain working diagnosis PSS to patients	4	83%	400
Knows how to formulate treatment goals together with patients and how to monitor progress	5	75%	381
Knows better how to motivate patients for behavior change	5	59%	381
Changed writing of letters about patients with PSS	6	83%	347
Knows when to refer a patient with PSS to mental healthcare	6	55%	347
Knows how to refer a patient with PSS to mental healthcare	6	66%	347

of 6 years [interquartile range (IQR) (3–20)]. Of the 801 participants, 22% rated their level of knowledge on PSS as adequate, and only 14% of participants indicated that they did *not* find patients with PSS difficult to deal with. Of all participants, 91% stated that they considered PSS a serious health problem and 50% indicated they had a special interest in PSS.

Participants generally rated their (improvements in) knowledge, skills, and attitude regarding the specific learning goals of the six modules as satisfactory, with at least 70% reporting improvements (**Table 3**). Exceptions are a change in attitude, a learning goal of the first module, that was only reported by 33%. In addition, the improvement in knowledge on motivating patients for behavior change (module 5) was reported by 59%, and knowledge on when and how to refer patients to mental healthcare in 55 and 66%, respectively (module 6).

## Self-Rated Knowledge, Skills, and Attitude on PSS

At the end of the course, 359 participants filled out the evaluative survey. After taking the course, 81% of participants rated their level of knowledge on PSS as adequate, and 86% felt that following the course increased their competencies in communicating with patients with PSS (see **Figure 1**). Of the participants who completed the full course, the range of time spend was 2–30 h (mean 7.8 h, mode 6 h).

## Satisfaction

When asked to grade the course, participants gave the course an overall mean score of 7.8 (SD 0.9, minimum-maximum 1–10). Accordingly, 85% would recommend the course to a colleague and 92% found that what they had learned during the course could be directly applied in their daily practice.

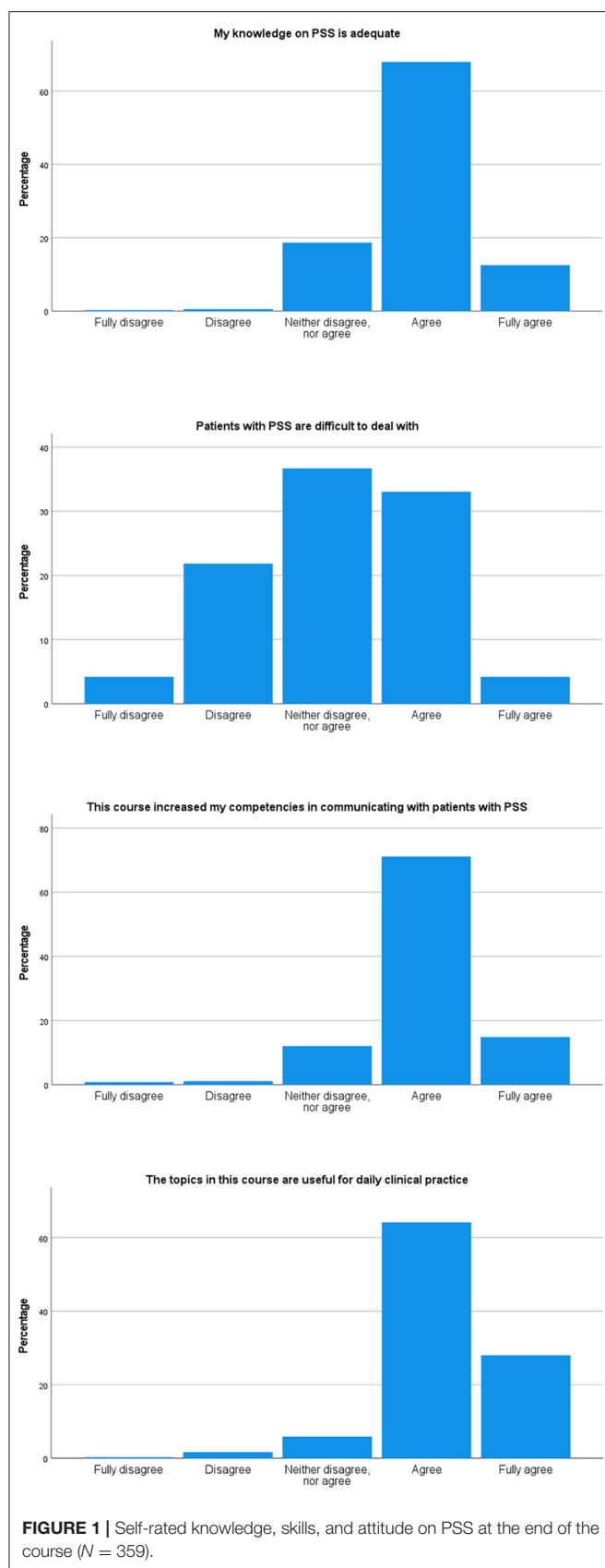
## DISCUSSION

In this study, we explored user experiences with an online, interprofessional course on PSS based on the biopsychosocial model. Our course developed in a co-design process involving multiple stakeholders can be implemented, is being used, and is positively evaluated by professionals across a variety of health care settings.

Our study confirms the findings of previous studies about the perspective of healthcare providers on patients with PSS and their ability to manage these patients. Our baseline survey shows that only 14% of participants did *not* find patients with PSS hard to deal with. This is in line with several previous studies, showing that physicians perceive patients with PSS as difficult, especially when they present with multiple symptoms (20, 21). In addition, 22% of our study participants rated their knowledge on PSS as adequate before taking the course. A previous survey amongst physicians also shows that a substantial proportion perceive themselves as insufficiently competent in managing patients with PSS (22). These findings highlight the need for education and training on PSS.

With regard to learning gains, participants generally rated their (improvements in) knowledge, skills, and attitude as satisfactory. Even though 73% indicated that the course had increased their awareness of their attitude toward PSS, only 33% reported that their attitude had actually changed. However, this is not necessarily a problem. At the start of the course, 91% of participants stated that they considered PSS a serious health problem, which suggests that these participants might already have had a positive attitude. Furthermore, a limited number of participants reported that they knew when (55%) and how (66%) to refer patients with PSS to mental healthcare. We therefore conclude this course topic needs revision and extra attention.

Participants who filled out the survey at the end of the course were satisfied with the course. This is in line with previous studies on e-learning in medical and nonmedical fields, which have



consistently demonstrated high satisfaction rates (23). Although we did not enquire appreciation for different aspects of the course (form, content, etc.), our findings indicate that e-learning is an appreciated form of education on the topic of PSS. This fits with a large body of literature pointing out the advantages of online learning, which include its flexibility, convenience, and self-controlled learning pace (16, 17, 24).

A strength of this study is the broad spectrum of healthcare providers included in the study. The course was developed with the help of many relevant stakeholders (PSS experts, education experts, healthcare professionals from different disciplines, and a patient representative), in order to be suitable for a large variety of healthcare providers. The group of participants represents the full spectrum of healthcare professionals from these different disciplines.

The most important limitation of the current study is the occurrence of several types of bias. First, self-selection by healthcare providers probably led to a selection bias. At baseline, 50% of participants indicated they had a special interest in PSS. This affinity might have increased their appreciation of the course content. On the other hand, some topics may have already been known and therefore considered redundant.

Secondly, attrition bias arose as a consequence of the manner of data collection. Participants were requested to (voluntarily) fill out several surveys, yet not all of them filled out all of the surveys. A large difference can be observed between the number of participants, who filled out the survey at the start of the course ( $N = 801$ ), and the number of participants, who filled out the survey at the end of the course ( $N = 359$ ). This might have influenced our results, since especially motivated participants might have completed the evaluation, and thus data are missing non at random (25). Apart from creating a bias in study results, attrition is a more general issue in e-learning, which requires more motivation and self-discipline than traditional teaching methods, such as lectures or workshops (16). Another limitation of this study is the lack of standardized, validated instruments to assess satisfaction and learning gains. A final limitation is our data collection in a real-world implementation setting. The evaluations were included in the e-learning, and it was not possible to couple the evaluations of the different modules due to the lack of a personal identifier in the data extracted from the learning management system. Therefore, we were not able to link evaluation data to personal characteristics and make statistical inferences (for instance, characteristics of completers / non-completers). This also implies that the data obtained before and after the training cannot be directly compared, since this would require an analysis on the sample that filled in both evaluations.

The current study explored learning gains through self-assessment by healthcare providers. Because the course aimed to improve patient-centered care, it would be interesting to study patients' perspectives of their healthcare providers' communication skills and attitude in the future. Another way to gain a more objective impression of improvements in knowledge, skills, and attitude, would be to let observers rate consultations before and after healthcare providers have taken the course.



The development of the course and conduction of the pilot study took place in the Netherlands. Thereafter, the course was translated into English and German, which allows the course to be used, studied, and further developed internationally. In addition, we are developing extra course modules with specific themes, such as PSS in children, mental health care for PSS and sex- and gender-sensitive care for PSS. The course could be further improved by involving stakeholders from the social domain, such as social workers. Accreditation of this course by the professional organization of social workers could improve the knowledge in skills in these professionals, and help to address the social aspects of the biopsychosocial model in patients with PSS.

In conclusion, according to healthcare providers, this online, interprofessional course is an effective and satisfying way to learn about PSS. Observer- and patient-rated outcomes are to be studied in the future.

## AUTHOR'S NOTE

Neither the manuscript nor any significant part of it is under consideration for publication elsewhere. A pilot study-based on 119/60 participants instead of 801/359 participants in the current study was published as part of a PhD thesis (<https://research.rug.nl/nl/publications/developing-e-health-applications-to-promote-a-patient-centered-ap>) but has not been submitted to a scientific journal or peer-reviewed previously. All authors listed have contributed significantly to the manuscript and consent to their names on the manuscript. In addition, all authors consent to publication.

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## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. The patients/participants provided their written informed consent to participate in this study.

## AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct and intellectual contribution to the work, and approved it for publication.

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# Attending a Biopsychosocially Focused Buprenorphine Training Improves Clinician Attitudes

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**Objective:** Substance use disorders remain highly stigmatized. Access to medications for opioid use disorder is poor. There are many barriers to expanding access including stigma and lack of medical education about substance use disorders. We enriched the existing, federally required, training for clinicians to prescribe buprenorphine with a biopsychosocial focus in order to decrease stigma and expand access to medications for opioid use disorder.

**Methods:** We trained a family medicine team to deliver an enriched version of the existing buprenorphine waiver curriculum. The waiver training was integrated into the curriculum for all University of Rochester physician and nurse practitioner family medicine residents and also offered to University of Rochester residents and faculty in other disciplines and regionally. We used the Brief Substance Abuse Attitudes Survey to collect baseline and post-training data.

**Outcomes:** 140 training participants completed attitude surveys. The overall attitude score increased significantly from pre to post-training. Additionally, significant changes were observed in non-moralism from pre-training ( $M = 20.07$ ) to post-training ( $M = 20.98$ ,  $p < 0.001$ ); treatment optimism from pre-training ( $M = 21.56$ ) to post-training ( $M = 22.33$ ,  $p < 0.001$ ); and treatment interventions from pre-training ( $M = 31.03$ ) to post-training ( $M = 32.10$ ,  $p < 0.001$ ).

**Conclusion:** Increasing medical education around Opioid Use Disorder using a Family Medicine trained team with a biopsychosocial focus can improve provider attitudes around substance use disorders. Enriching training with cases may improve treatment optimism and may help overcome the documented barriers to prescribing medications for opioid use disorder and increase access for patients to lifesaving treatments.

**Keywords:** substance use disorder, opioid use disorder, stigma, biopsychosocial, medications for opioid use disorder

## INTRODUCTION

Substance use disorders (SUDs) are among the most stigmatized conditions in the US and around the world (1). Furthermore, stigma against people with opioid use disorder (OUD) and other SUDs affect the frequency with which people are offered effective treatment as well as how often they are willing to engage in care (2). Clinicians explicitly acknowledge treatment pessimism and

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negative stereotypes about patients with OUDs as a barrier to offering care (3, 4). The recent COVID-19 pandemic has highlighted the shortfalls of the current behavioral health treatment system and the additional risks for patients with underlying mental health issues (5). Efforts to increase the understanding of substance use disorders as a chronic disease have highlighted the underlying neurobiological changes and focused on biomedical approaches to treatment. At times this approach may have furthered the stigma surrounding opioid use disorder (6). The term “Medication Assisted Therapy” or MAT is different than the terminology surrounding pharmacotherapy for any other chronic disease. For example, we would never describe the use of metformin for diabetes as medication assisted treatment or say medication assisted treatment when advocating for diuretics for blood pressure management.

Medications for opioid use disorder (MOUD), including buprenorphine, have been shown to decrease risks of overdose and increase retention in treatment (7). Unfortunately, many patients are unable to access this treatment due to lack of providers able to prescribe the medication (8).

Many clinicians do not receive robust training around SUD treatment in undergraduate and graduate medical education (9) and medical providers frequently cite concerns related to working with patients with OUD as one of the barriers to prescribing medications for OUD thus further worsening patients’ access to care (10, 11). In the United States, where this study was completed, until recently clinicians had to certify 8 h of nationally approved additional training in SUD for physicians and 24 h of additional training for Advance Practice Practitioners (APPs) or see patients in a specially licensed facility to be able to prescribe MOUD. There has never been a study looking at which type and how much education is critical to improve clinicians’ understanding and attitudes about SUDs. Some have argued that requiring additional training and a special license increases the stigma toward treating patients with OUD and decreases access to MOUD (12). In April 2021, the national laws changed to allow clinicians with an active DEA license to submit a notice of intent (NOI) to prescribe buprenorphine with a patient limit of 30 *without* certifying to any additional training (13).

The removal of the requirement of a certified training is an important first step to increasing access. However, in order to increase the numbers of clinicians who are actively prescribing MOUD, providers will likely need some training and education to overcome the stigma attached to substance use and to understand opioid use disorder as a chronic disease with treatment that must address the biopsychosocial needs of the patients (14). In Primary Care, our fundamental goal is to support patient disease prevention and manage understanding the interplay of biologic, social and psychiatric factors (15). Evidence from multiple continents including Europe, Australia and North America indicates that expanding access to treatment of OUD in Primary Care can decrease mortality rates without increasing the burden on clinicians (16). Substance use disorder training that focuses on expanding the comfort and knowledge of primary care clinicians to manage the long-term treatment of substance use disorders may increase access to critically needed, patient centered care for these conditions.

## MATERIALS AND METHODS

### Intervention

We received a grant to deliver nationally approved buprenorphine waiver trainings given by a primary care team at no cost across multiple settings in a 13-county region surrounding Rochester, New York. This study looked at the effect of these buprenorphine waiver trainings on clinician attitudes toward persons with SUDs. Our faculty worked with experts in the field to become certified to deliver nationally recognized trainings on all forms of OUD treatment through the American Society of Addiction Medicine (ASAM) and the American Academy of Addiction Psychiatry (AAAP). We received permission to add local data, a case that highlighted our experience from a Family Medicine perspective and anecdotes about our experience prescribing buprenorphine including how to gain acceptance from office staff and practice partners to the nationally approved waiver training slides. The biopsychosocial model acted as a framework to guide our training approach. We promoted the understanding of SUDs as a heritable chronic disease with well-documented biologic predisposition. We reviewed the frequency of mental health comorbidities in patients with SUDs and encouraged our trainees to bridge the communication gap between psychiatric care, SUD treatment and primary care. The case we added to the training highlighted the role of psychosocial stressors as potential triggers for relapse and outlined how a comprehensive biopsychosocial approach can keep patients engaged in treatment (see **Table 1** for description of case and **Figure 1** for the urine drug screen results). The primary training team consisted of two Family Medicine physicians and one Nurse Practitioner who were trained at the University of Rochester in the Biopsychosocial model (17) and brought a combined 30 years of experience managing patients with SUDs in a primary care setting. Our focus on myth busting around concerns that treating patients with OUD would be dangerous and difficult as well as the personal and professional satisfaction that comes with adding this clinical skill helped address the biopsychosocial needs of the clinicians, and office staff.

### Setting/Participants

We worked with area primary care residency programs and regional hospitals to schedule the trainings. Participants then completed the 4–4.5-h live portion of either the AAAP or ASAM mixed waiver training. Ability to participate was not restricted to specific health systems and as such participants came from 11 different health systems and both rural and urban settings.

### Instruments

We utilized the 25-item Brief Substance Abuse Attitudes Survey (BSAAS) to measure provider attitudes toward SUD (12). The survey has been previously validated among health care providers and shown good validity and reliability (12). The items are scored using a 5-point Likert Scale, with higher scores indicating a more positive attitude toward SUD. We scored the BSAAS using its published scoring metric. We calculated an overall score for BSAAS, as well as scores for the



**TABLE 1 |** Case presentation.**Case presentation**

- 35 year old female transferred primary care/buprenorphine management (considered stable).
- In recovery for 11 months, completed a 1 year intensive program and continuing outpatient care
- Substance Use Disorder history: Started with oral opioids after an arm fracture. Moved on to heroin. States she has used “everything.”
- At first visit she reports that she is still having cravings at 16 mg/day; requesting increase to 20 mg and states that is what she was on until she had insurance issues.
- Health history: Depression, on Citalopram
- Social History: has steady employment; recent breakup, going to family court to regain custody of kids.
- Plan: Urine Drug Screen (UDS), Labs, Contraception

Patient continues to do well and keeps follow-up appointment. Very happy to have her 2 young children home.  
Then a shift occurs...

- Not getting any help with kids as current partner doesn't see it as his responsibility.
- Trying to balance children/work/appointments.
- Turns out she never started her Oral Contraception prescribed at initial visit, became pregnant and then miscarried.
- UDS: See Results (**Figure 1**).
- Patient called by RN to come in to the office for shorter interval appointment, however she was away on a trip.
- Next visit patient adamantly denied diversion/relapse, became very angry during the visit and walked out of exam room.

For discussion: Is this patient appropriate to continue in a primary care setting? How would you approach the management of this situation?

Later in visit: Patient admitted that the inappropriate urines were not hers. She was using someone else's to hide her marijuana use.

For discussion: What are treatment options for this patient? What are risk factors for continued relapse? What would a harm reduction approach look like for this patient?

scale's five sub-scales (permissiveness, treatment intervention, non-stereotypes, treatment optimism and non-moralism). We added three questions to the BSAAS asking participant opinions regarding how effective buprenorphine treatment was for OUD, how reasonable treatment for OUD was in their practice and the degree that barriers existed in their practice to prescribe buprenorphine. We collected the survey at pre (prior to the start of a mixed, half in-person, half-online buprenorphine waiver training) and post (after the live course). We assigned each participant and a randomly assigned numerical number and retrospectively paired the surveys.

Standard demographic information was collected separately and not associated with the survey data due to concerns around protecting privacy (**Table 2**).

## Analyses

Survey completion was voluntary, with informed consent and administered across seven trainings from May 2019 to February 2020A missing value analysis was conducted to examine the amount and pattern of missing data. Descriptive statistics for

Urine Lab	ng/mL
Buprenorphine	>1000
Buprenorphine Glucuronide	<5
Norbuprenorphine	27
Norbuprenorphine Glucuronide	<5
Total Norbuprenorphine	27
Total Norbuprenorphine/Creatinine	25
Creatinine	108

**FIGURE 1 |** Urine drug screen (UDS) results.

the whole sample ( $N = 142$ ) indicated that if applying listwise deletion >5% of data would be missing. We removed two cases with 50% of missing data or no post-test scores leaving an analytic sample of ( $N = 140$ ) observations. Patterns of missingness were tested using Little's (1988) MCAR test. Data were found to be missing completely at random (MCAR) 2. Stochastic, regression-based, single imputation was used to handle all missing values for both pre- and post-test variables that comprise the BSAAS. Random error was introduced to the model to protect against narrow standard errors as a result of overfitting. Pre, post, and sub-scale scores of the BSAAS were computed and included in the model as predictors. Following imputation, subscales and total scores were recalculated.

Data management and analysis was conducted using SPSS v.26. Dependent *t*-tests were conducted on each of the five sub-scales comprising the BSAAS. Higher scores indicated more positive opinions.

## Sub-analyses

We collected demographic data separately from the attitude survey data in order to protect the privacy of our participants and to provide our funders with individual level data about who participated in the training and went on to get their “x wavier” and prescribe buprenorphine. Full demographic data was collected from 137 participants. We were not able to examine subgroup differences. The University of Rochester's Institutional Review Board (IRB) approved this study.

## RESULTS

A total of 142 individuals completed surveys out of a potential 217 subjects. Two cases were removed due to no post-test scores, leaving an analytic sample ( $N = 140$ ) of paired observations (65% completion rate).

## Provider Attitudes

The overall attitude score increased significantly from pre- to post-training. Additionally, significant changes were observed in non-moralism from pre-training ( $M = 20.07$ ) to post-training ( $M = 20.98$ ,  $p < 0.001$ ); treatment optimism from pre-training ( $M = 21.56$ ) to post-training ( $M = 22.33$ ,  $p < 0.001$ ); and treatment interventions from pre-training ( $M = 31.03$ ) to post-training ( $M = 32.10$ ,  $p < 0.001$ ). No effect was observed for the scales non-stereotype or permissiveness.

**TABLE 2 |** Demographic and clinical characteristics.

Characteristic			N	(%)
Gender	(N = 137)	Female	62	45.3
		Male	72	52.6
		Non-binary/3rd gender	1	0.7
		Prefer not to disclose	2	1.5
Age	(N = 138)	25–34	74	53.6
		35–44	28	20.3
		45–54	20	14.5
		55–64	14	10.1
		65+	2	1.4
Specialty	(N = 138)	Addiction medicine	3	2.2
		Emergency medicine	26	18.8
		Family medicine	34	24.6
		Geriatrics	4	2.9
		Internal medicine	19	13.8
		Pediatrics	3	2.2
		Obstetrics and gynecology	2	1.4
		Other	15	10.9
		Psychiatry	26	18.8
		Palliative care	5	3.6
		Surgery	1	0.7
Years in clinical practice	(N = 138)	0–5 Years	61	44.2
		6–10 Years	11	8
		11–15 Years	9	6.5
		16–20 Years	9	6.5
		20–30 Years	11	8
		30+ Years	8	5.8
Role	(N = 138)	I am not in clinical practice	29	21
		Administrative	3	2.2
		Nurse practitioner	18	13
		Other	5	3.6
		Resident	7	5.1
		Physician	79	57.2
		Physician assistant	3	2.2
		Student	23	16.7

In addition to the BSAAS, questions assessed participant opinions regarding how effective buprenorphine treatment was for OUD and how reasonable treatment for OUD was in their practice. Significant changes were observed for effectiveness of buprenorphine from pre-training ( $M = 4.14$ ) to post-training ( $M = 4.5$ ,  $p < 0.001$ ) and for how reasonable treatment for OUD is in their practice from pre-training ( $M = 3.87$ ) to post-training ( $M = 4.24$ ,  $p < 0.001$ ) (see **Table 3** for full results).

## DISCUSSION

The results of this preliminary study show that attending a biopsychosocially focused, buprenorphine waiver training delivered by a primary care team can significantly change attitudes toward patients with substance use and improve treatment optimism. Strengths of this study include its relatively

large sample size as compared to other studies looking at provider attitude changes and the fact that we were able to pair our pre-post survey results. Additionally, our study includes results from different levels of training, multiple specialties and types of clinicians, indicating that change in attitude is not limited by individual characteristics. Previous studies have shown resident attitudes decline toward patients with substance use during residency (18), but that exposure to additional training in addiction can improve attitudes toward persons with SUD (19, 20). A recent study of medical students indicated that traditional buprenorphine waiver training alone is not enough to decrease stigma (21). A biopsychosocial focus may be the element that can help improve clinician attitudes toward this patient population.

Federal regulations previously required 8 h of training for physicians and 24 h of training for Advance Practice Practitioners in order to prescribe buprenorphine for OUD. The authors feel that the value of attending the training is in understanding more about the nature and course of substance use disorder rather than specific skills required to prescribe buprenorphine. This can likely be accomplished in <8 h and may have greater value early on in medical training, rather than later in a career when patterns and stereotypes are deeper ingrained (22). We believe this study provides preliminary evidence for the role of increasing exposure to a biopsychosocially focused SUD curriculum with a focus on decreasing the stigma associated with SUD.

The non-randomized design is a limitation to the study. Attendance was required for some resident and faculty learners, however others attended voluntarily and not all participants chose to complete the survey which may have led to a group that was predisposed to a positive attitude change. Another limitation is the limited geographic range of the trainings. It is possible that stigma and attitudes may differ depending on regional variations of historical experiences and rates of opioid abuse. Additionally, we used a validated survey for provider attitudes, however we added several questions related specifically to buprenorphine prescribing at the end of the survey, which may affect the validation. Another limitation is that we administered the post-test immediately after the training. In order to protect the privacy of our participants and due to follow-up data requirements from our funders, we collected the demographics separately from the survey data and so we were not able to do a sub-group analysis to see if there were differences in attitude changes based on the gender, level of training or specialty. Further research is needed to determine if the attitude shift is maintained over time and if there are subgroup changes in attitude changes based on level of training, specialty or gender.

## CONCLUSION

Increasing medical education around substance use disorders is a critical next step to decreasing stigma around this disease and improving access to treatment. It is likely that the full 8 or 24 h are not required to change attitudes. The previous, federally required training is not an evidenced based educational intervention. Now that the laws have changed to remove the requirement for a specific training larger, randomized controlled studies are needed

**TABLE 3 |** Summary of pre- and post-training results.

	Pre-training		Post-training		<i>t</i> (df)	<i>P</i>	95% CI	
	M	SD	M	SD			Lower	Upper
Non-Moralism	20.07	2.60	20.98	2.79	5.89 (139)	<0.001	0.61	1.22
Treatment optimism	21.56	2.45	22.33	2.30	5.27(139)	<0.001	0.48	1.06
Non-stereotype	12.07	1.70	12.12	1.74	0.49(139)	0.62	−0.17	0.28
Treatment interventions	31.03	3.17	32.10	3.35	4.97(139)	<0.001	0.65	1.50
Permissiveness	10.35	2.42	10.33	2.97	0.09(139)	0.93	−0.35	0.32
*Full BSAAS	95.07	7.47	97.87	7.83	6.42(139)	<0.001	1.94	3.67
Effectiveness of Buprenorphine	4.14	0.72	4.50	0.71	5.57(139)	<0.001	0.23	0.48
Treatment for OUD in your practice	3.87	0.90	4.24	0.70	4.75(139)	<0.001	0.22	0.52

*M*, mean; *SD*, standard deviation; *t*, *t*-value from the dependent *t*-test; *df* = degrees of freedom; *p* = significance (two-tailed, *p* < 0.05); *CI*, confidence interval.

\*BSAAS: [https://medicine.yale.edu/sbirt/curriculum/modules/medicine/brief\\_substance\\_abuse\\_attitude\\_survey\\_100733\\_284\\_13474\\_v1.pdf](https://medicine.yale.edu/sbirt/curriculum/modules/medicine/brief_substance_abuse_attitude_survey_100733_284_13474_v1.pdf).

to determine if our biopsychosocially focused, cased based approach, or if having a team of primary care clinicians direct the intervention, is the critical aspect for changing clinicians understanding and attitudes toward substance use disorders. Additionally, there should be consideration of including high yield elements from the buprenorphine waiver training as a routine requirement for undergraduate medical education to standardize the message received by clinicians in training.

## DATA AVAILABILITY STATEMENT

The datasets presented in this study can be found in online repositories. The names of the repository/repositories and accession number(s) can be found at: <https://app.box.com/s/vkqomvxqsey1d91dyp3tmbb0tp7704w8>.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Rochester School of Medicine and Dentistry RSRB. Written informed consent for participation was

not required for this study in accordance with the national legislation and the institutional requirements.

## AUTHOR CONTRIBUTIONS

BS cleaned the data, analyzed, interpreted the baseline, and post-training data. EL, HR, and MS interpreted the data analysis and contributed to writing the manuscript. All authors read and approved the final manuscript.

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# Adherence to Traditional Chinese Postpartum Practices and Postpartum Depression: A Cross-Sectional Study in Hunan, China

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**Background:** The relationship between adherence to traditional Chinese postpartum practices (known as “doing-the-month”) and postpartum depression (PPD) remains unknown. Practices including restrictions on diet, housework and social activity, personal hygiene, and cold contact, could introduce biological, psychological, and socio-environmental changes during postpartum.

**Methods:** The cross-sectional study included 955 postpartum women in obstetric clinics in Hunan Province of China between September 2018 to June 2019. Thirty postpartum practices were collected by a self-report online structured questionnaire. Postpartum depression symptoms were assessed by the Chinese version of the Edinburgh Postnatal Depression Scale (EPDS). Multivariable linear regression was used to estimate the differences in EPDS scores according to adherence to postpartum practices. Firth’s bias-reduced logistic regression was employed to analyze the binary classification of having PPD symptoms (EPDS  $\geq 10$ ).

**Results:** Overall, both moderate and low adherence to postpartum practices appeared to be associated with higher EPDS scores (adjusted difference 1.07, 95% CI 0.20, 1.94 for overall moderate adherence; and adjusted difference 1.72, 95% CI 0.84, 2.60 for overall low adherence). In analyses by practice domain, low adherence to housework-related and social activity restrictions was associated with having PPD symptoms compared with high adherence (OR 1.61, 95% CI 1.07, 2.43).

**Conclusions:** Low adherence to traditional Chinese postpartum practices was associated with higher EPDS scores indicating PPD symptoms, especially in the

domain of housework-related and social activity restrictions. Psychosocial stress and unsatisfactory practical support related to low adherence to postpartum practices might contribute to PPD. Longitudinal study and clinical assessment would be needed to confirm these findings.

**Keywords:** postpartum practices, doing-the-month, postpartum depression, EPDS, China

## INTRODUCTION

The weeks following delivery are a critical period for the long-term health and well-being of the mother and her infant(s) (1). Globally, many cultures observe specific postpartum practices to help the mother recuperate after birth (2). Although postpartum practices vary across cultures, most of them include postnatal care for the mother in a 30–40-day period of rest (3). In Chinese cultures, postpartum practices have been particularly well-documented into a systematic custom known as “doing-the-month” or “confinement” (4). During the 1-month confinement period, Chinese postpartum women are expected to follow many stringent restrictions regarding diet, hygiene, housework-related and social activities, and cold contact (5–7). These traditional restrictions could introduce complex non-uniformed co-occurring but controversial biological, psychological, and socio-environmental changes during postpartum (7–9), of which the health impacts are hard to quantify and have not yet been comprehensively investigated.

Overlapping with the confinement period, postpartum depression (PPD) is one of the most common and disabling but easily unnoticed complications of child-bearing (6, 10), affecting approximately 10–20% of women across different cultural settings (10, 11). Postpartum depression is the major unipolar depressive disorder that occurs in the year after giving birth, with onset mainly within the first 6 weeks postpartum according to International Statistical Classification of Diseases, 10th Revision (ICD-10) (4, 12). Postpartum depression does not only cause maternal morbidity, characterized by episodes of guilt, irritability, exhaustion, anxiety, and sleep disorders (12), but also disrupts downstream infant care and family dynamics (13, 14). Postpartum mental health problems in low- and middle-income countries were suggested to be more severe than those in high-income countries (14, 15). The reported prevalence of PPD in China ranged from 9.4 to 27.4% (16), which could be underestimated due to low public awareness and stigma about mental disorders (17), and could vary according to reporting style (11) or screening timing (18). The identified risk factors of PPD are multifactorial, involving physical, emotional, and social factors (19), suggesting a potentially important role of “doing-the-month” that can fulfill biopsychosocial elements in the etiology or the prevention of PPD (20, 21).

In the Chinese culture, a high adherence to doing-the-month (to follow most traditional postpartum practices) is intended to guarantee practical and social support for the mother, and to promote maternal physical and mental health (4, 22). However, the impact of the adherence to the postpartum practices on PPD remains unknown.

In a systematic review including 16 studies in predominantly Chinese populations (4), eight studies suggested that doing-the-month was associated with a protective effect on PPD (5, 7, 23–28), while four studies indicated the opposite (29–32) and four showed null effect (33–36). The mixed evidence was further complicated by the heterogeneity of “doing-the-month” (6, 22, 34, 37), such as the number, content, and domain of adhered postpartum practices. In most of the previous studies, “doing-the-month” was investigated as a unitary practice, whereas indeed it constitutes practices in diet, hygiene, housework-related and social activities, and cold contact with different adherence levels in the population (5). Existent investigations are inadequate on the health impact of adherence to each specific domain. In addition, primary caregiver (4), parity (38), medical care coverage, and quality (39) may modify the relationship between adherence to postpartum practices and PPD.

Studying the health implications of Chinese postpartum practices might gain valuable insights into prevention or early intervention for mental disorder in the perinatal period in Chinese and other populations. In this cross-sectional study, we aimed to explore the associations between adherence to the traditional Chinese postpartum practices and PPD among postpartum women in Hunan province of China. We hypothesized that adherence to the traditional Chinese postpartum practices is associated with PPD.

## MATERIALS AND METHODS

### Study Setting and Participants

This is a cross-sectional study conducted in Hunan Province in China between September 2018 to June 2019. The participants were recruited from Hunan Provincial Maternal and Child Health Care Hospital (MCHH) in Changsha and several rural township health centers and urban community health centers in Hunan Province. All potential participants were contacted by researchers when they came for their postnatal appointments (4–10 weeks after delivery), mostly for the routine postpartum examination (around 42 days after delivery) in obstetric clinics. Electronic informed consent was obtained at the enrollment along with an online self-administered questionnaire administered through mobile phones. The women were included if they: (1) were at 4–10 weeks after delivery; (2) owned a cellphone; and (3) could understand and respond to the online questionnaire in Chinese. All participants were invited by trained research staff to complete the online questionnaire on their cellphones after the appointments in the obstetric clinic, with immediate

assistance available to potential inquiries during data collection. This study protocol was approved by the ethical review committee of Xiangya School of Public Health Central South University.

Thousand hundred and twenty-six postpartum women were initially invited with 68 excluded due to having birth less than 4 weeks or more than 10 weeks at enrollment, and 3 individuals who provided the same response for all items in the questionnaire were also excluded. The remaining 955 women were included in the study, 632 from MCHH in Changsha and 323 from other municipalities in Hunan Province (**Appendix 1** in Supplementary Material).

## Assessment of Adherence to Chinese Postpartum Practices

The exposure of interest was the adherence to Chinese postpartum practices. We adapted a "Practice of Doing-the-month Questionnaire" that has 30 items under four domains (9 under restriction on diet, 14 under restriction on housework-related and social activities, 4 under restrictions on personal hygiene, and 3 under restriction on cold contact) (5). For adherence to each item, participants responded with "yes" or "no." The content validity index and Cronbach's  $\alpha$  of the original questionnaire were 0.95 and 0.86, respectively (5). Questionnaire revision was based on evidence from a pre-testing study in Hunan, without errors from translation (**Appendix 2** in Supplementary Material). To minimize missing data, the electronic questionnaire was designed in a "must-enter" format for all items regarding postpartum practices. Additionally, other information regarding postpartum practices was collected at the same time (i.e., location for postpartum practices, primary caregiver, satisfaction with experience of conducting postpartum practices), as well as sociodemographic, obstetric, and psychological characteristics. The satisfaction with experience of conducting postpartum practices was evaluated by a five-level Likert scale, with scores ranging from 1 (least satisfactory) to 5 (most satisfactory).

## Assessment of Postpartum Depression Symptoms

The primary outcome was PPD assessed by the Chinese version of the Edinburgh Postnatal Depression Scale (EPDS) (40, 41). The Chinese EPDS has been validated to show satisfactory specificity and sensitivity for early identification of PPD (40, 41). The 10 items, scored as 0, 1, 2, or 3 to indicate increasing symptoms, explored mood, pleasure, guilt, anxiety, fear, ability to cope, insomnia, sadness, and self-injury. The total score is calculated by summing the scores of each item, with a maximum score of 30. EPDS  $\geq 10$  was classified as having PPD symptoms in this study, as for the Chinese women the 9/10 threshold performs substantially better than the conventional 12/13 threshold in identifying depression (42). The internal consistency of the EPDS scale, as assessed by Cronbach's  $\alpha$  in this study, was 0.89.

## Statistical Analysis

Firth's bias-reduced logistic regression (43) using R package "logistf" (44) was employed to estimate the odds ratio (OR)

and 95% confidence interval (CI) of having PPD symptoms according to adherence to postpartum practices. Multivariable linear regression was used to estimate the mean differences in continuous EPDS scores. Adherence was first categorized into "high," "moderate," and "low" levels according to the tertile counts of adhered items (yes = 1, no = 0) with a total score of 30. Moreover, this tertile categorization of adherence was applied for satisfaction with the experience of conducting postpartum practices, and four practice domains with a total score of 9, 4, 14, 3 for diet, hygiene, activity, and cold contact, respectively. Furthermore, tertile adherence to every domain was analyzed with and without mutually adjusting for other tertile practice domains, and every single item was analyzed with and without mutually adjusting for items within domains. We conducted trend tests using the Likert scale of satisfaction or the counts of adhered items as a continuous variable. We adjusted for potential confounders including education level, planned pregnancy, family history of PPD, depression diagnosis before pregnancy, primary caregivers, and recruitment locations (MCHH or not). In additional analyses, we adjusted for maternal age, household income level, occupation, parity, the health status of the newborn baby, expected gender of the newborn baby, feeding mode to evaluate influence from these factors. Maternal age extracted from clinic information system had a missing value for 201 participants. Since in total only approximately 2% of participants had missing values on other covariates, we excluded them in the regression analyses. Additionally, we performed stratified analyses to evaluate potential effect measure modification by recruitment locations, parity, primary caregivers. We performed tests of heterogeneity by evaluating the *p*-value of the interaction term between each exposure variable and the potential modifying factors. Furthermore, we performed a cluster analysis on 30 postpartum practices to investigate the relationship between practice patterns and PPD (**Appendix 3** in Supplementary Material) using the FactoMineR package (45, 46).

## RESULTS

**Table 1** presents the characteristics of the study sample. Overall, 73.4% of the participants had a bachelor or a graduate degree, 54.0% of women have had given birth previously, and 63.5% were planned pregnancies. Only 18 (1.8%) women had a history of depression before pregnancy and 30 (3.1%) reported a family history of PPD. Using predefined 9/10 as the cut-off point of EPDS as afore-mentioned, 36.8% were classified as having PPD symptoms.

Overall, participants had various satisfactory levels toward the experience of conducting postpartum practices. Over 70% of participants reported a medium or higher rating ( $\geq 3$ ) regarding the experience of conducting postpartum practices, whereas <20% of participants gave the highest rating (5/5) (**Table 2**, **Supplementary Table 1**).

**Table 2** shows the associations between PPD symptoms and the satisfactory rating or adherence to traditional Chinese postpartum practices. A lower rating on postpartum practice experience was associated with higher odds of PPD symptoms

( $P$  for trend  $<0.001$ ). The OR estimates were 1.11 and 1.26 for moderate and low adherence groups, respectively, though the CIs included null values.

Among the four domains in postpartum practices, low adherence to housework-related and social activity restrictions was associated with symptoms of PPD compared with the high adherence group (Table 2). The OR for low adherence to activity restrictions was 1.61 (95% CI 1.07, 2.43) and the  $P$  for trend was 0.061, without adjusting for other domains. The suggestive trends in associations for decreasing restrictions on housework-related and social activity were strengthened in the model mutually adjusting for other domains simultaneously ( $P$  for trend 0.022).

**TABLE 1 |** Socio-demographic and obstetric characteristics of postpartum women in Hunan, China, 2018–2019 ( $n = 955$ ).

	N	(%)
<b>SOCIO-DEMOGRAPHIC CHARACTERISTICS</b>		
<b>Ethnicity</b>		
Han	926	(97.0)
Others	29	(3.0)
<b>Residence address</b>		
City	728	(76.2)
Town	86	(9.0)
Village	141	(14.8)
<b>Occupation</b>		
Civil servant	208	(21.8)
Company employee	257	(26.9)
Self-employed people	82	(8.6)
Farmers and peasant workers	51	(5.3)
Others	357	(37.1)
<b>Education</b>		
Under senior high	79	(8.3)
Senior high	175	(18.3)
Bachelor	600	(62.8)
Graduate	101	(10.6)
<b>Monthly household income (kRMB)</b>		
<5	167	(17.5)
5–10	324	(33.9)
10–15	207	(21.7)
15–20	116	(12.1)
>20	141	(14.8)
<b>OBSTETRIC CHARACTERISTICS</b>		
Planned pregnancy	606	(63.5)
First pregnancy	439	(46.0)
Gender of baby consistent with expectation	709	(74.2)
<b>Delivery mode</b>		
Vaginal delivery	576	(60.3)
Cesarean delivery	379	(39.7)
<b>Infant feeding</b>		
Exclusive breast-feeding	572	(59.9)
Exclusive formula-feeding	49	(5.1)
Mixed feeding	334	(35.0)

While no apparent associations were found for having PPD symptoms and the restrictions on diet, personal hygiene, or cold contact.

Analyses for the mean difference in continuous EPDS scores showed similar findings with binary PPD symptoms in both overall and domain adherence, where both moderate and low adherence to postpartum practices appeared to be associated with higher EPDS scores (adjusted difference 1.07, 95% CI 0.20, 1.94 for overall moderate adherence; and adjusted difference 1.72, 95% CI 0.84, 2.60 for overall low adherence,  $P$  for trend  $<0.001$ ) (Table 3).

The numbers of women reporting adherence were varied across postpartum practices, generally with the lowest adherence to restrictions on personal hygiene, while the highest adherence in avoiding sexual intercourse (Supplementary Table 2). Analyses for each practice item showed adherence to many housework-related and social activity restrictions were independently associated with lower EPDS scores. For diet, personal hygiene, and cold contact constraint, there were no consistent patterns found for single items. Some associations were observed for single items, but the results were inconsistent after accounting for other items within the category.

No apparent effect modifications were observed for recruitment location, parity, primary caregiver in associations between postpartum practices and PPD symptoms (Supplementary Table 3).

Three clusters were identified based on adherence to each postpartum practice, which may reflect the degree of adherence to these items (Figure 1). Specifically, Cluster 1 (343/955) was characterized as following very few practices. In contrast, Cluster 3 (96/955) conducted almost all practice items in each domain. Cluster 2 (516/955), the largest cluster, had a mixed adherence to postpartum practices. Regression analysis using the cluster variable as a predictor suggested low adherence to postpartum practices was associated with having PPD symptoms compared with the mixed adherence, while the cluster with almost all items completed did not show a strong association (Table 4, Supplementary Table 4).

Supplementary Table 5 shows numbers of overall adhered items and within every practice domain in each cluster that differed from each other ( $P < 0.001$ ). Consistently, Cluster 1 (very few practices adhered) was over-represented by having PPD symptoms, also linked to the least satisfactory level of "doing-the-month" experience (1 out of 5 scores).

In addition, the results did not markedly change in models further adjusted for more social-demographic and obstetric characteristics in sensitivity analyses. Finally, our findings did not change when accounting for maternal age when using a smaller sample size ( $n = 754$ ).

## DISCUSSION

In this study, we evaluated the associations between adherence to the traditional Chinese postpartum practices ("doing-the-month") and depressive symptoms in women during 4–10 weeks postpartum in Hunan, China. We found that low



**TABLE 2 |** Odds Ratio (OR) for PPD symptoms (EPDS scores  $\geq 10$ ) according to postpartum practice adherence<sup>a</sup>.

	EPDS scores $\geq 10$ vs. $<10$				
Postpartum practices	N	Model1 <sup>b</sup> OR	(95% CI)	Model2 <sup>c</sup> OR	(95% CI)
<b>Satisfaction with experience<sup>d</sup></b>					
High rating (4–5)	377	1.00	(Reference)	/	
Not bad (3)	317	1.40	(0.95, 2.05)	/	
Low rating (1–2)	240	2.25	(1.40, 3.63)	/	
<b>Overall adherence<sup>e</sup></b>					
High adherence (18–30)	294	1.00	(Reference)	/	
Moderate adherence (14–17)	306	1.11	(0.74, 1.68)	/	
Low adherence (0–13)	356	1.26	(0.82, 1.94)	/	
<b>Restriction on diet</b>					
High adherence (7–9)	239	1.00	(Reference)	1.00	(Reference)
Moderate adherence (5–6)	353	0.99	(0.63, 1.54)	1.05	(0.65, 1.68)
Low adherence (0–4)	363	0.98	(0.62, 1.53)	0.95	(0.58, 1.56)
<b>Restriction on housework-related and social activity</b>					
High adherence (9–14)	313	1.00	(Reference)	1.00	(Reference)
Moderate adherence (7–8)	253	1.16	(0.75, 1.78)	1.24	(0.80, 1.94)
Low adherence (0–6)	389	1.61	(1.07, 2.43)	1.81	(1.13, 2.90)
<b>Restriction on personal hygiene</b>					
High adherence (2–4)	207	1.00	(Reference)	1.00	(Reference)
Moderate adherence (1)	247	1.04	(0.62, 1.73)	0.89	(0.52, 1.51)
Low adherence (0)	501	0.79	(0.50, 1.23)	0.65	(0.39, 1.08)
<b>Restriction on cold contact</b>					
High adherence (3)	442	1.00	(Reference)	1.00	(Reference)
Moderate adherence (2)	284	1.04	(0.70, 1.54)	1.01	(0.66, 1.53)
Low adherence (0–1)	229	1.13	(0.73, 1.74)	1.01	(0.61, 1.67)

<sup>a</sup>Binary logistic regression was used to estimate odds of PPD symptoms (EPDS scores  $\geq 10$ ) compared with EPDS Scores  $<10$ .

<sup>b</sup>Model1 adjusted for education level (under bachelor, bachelor/graduate), planned pregnancy (yes, no), family history of postpartum depression (yes, no), depression diagnosis before pregnancy (yes, no), primary caregiver during 1-month postpartum (own mother, mother-in-law, husband/self, all others), recruitment location (Hunan provincial maternal and child health care hospital in Changsha, any other clinic).

<sup>c</sup>Model2 additionally mutually adjusted other practice domains based on Model1.

<sup>d</sup>Scores ranged from 1 (least satisfactory) to 5 (most satisfactory).

<sup>e</sup>Adherence was determined by number of completed items.

and moderate adherence to postpartum practices, as well as lower satisfactory ratings on “doing-the-month” experience, was associated with PPD. This impact was particularly consistent in the domain of housework-related and social activity restrictions. Cluster analyses confirmed the findings where women following very few practices were over-represented by having PPD symptoms and dissatisfaction toward the experience of “doing-the-month.”

Previous studies on “doing-the-month” have addressed both the health benefits or detriments of the Chinese postpartum practices, with inconsistent conclusions on mental effect (4, 37, 38). One major issue is that the naive exposure classification failed to capture the diverse domains of postpartum practices and overlooked the biopsychosocial functioning of practice patterns. Among little evidence considering the heterogeneity of postpartum practices, the estimated impact on PPD is also controversial. One study involving 202 Taiwanese women at 4–6 weeks after birth found that every 1-score increment out of the total 108 adherence scores to postpartum practices

decreased the odds of PPD by 0.97, after adjusting education, parity, infant feeding mode, location for “doing-the-month” (5). By contrast, another study in Wuhan, Hubei province using the same version of questionnaire showed a crude positive association between adherence to “doing-the-month” and PPD at 6 weeks (22). These findings show that the differences in study populations (e.g., sample size, parity, socio-economic class), in outcome measurement (e.g., screening questionnaires used and the timing), and in confounding control might also lead to mixed findings.

Briefly, the association of low adherence to postpartum practices with PPD in the current study might be explained by the biopsychosocial model of illness development (20, 21) and the causal pie model of outcome occurrence (47, 48). For instance, interactions of certain factors under biological, psychological and social domains could form sufficient causal mechanisms and trigger PPD occurrence. Our findings might reflect mechanisms including biopsychosocial changes such as elevated psychosocial stress and unsatisfactory social support associated

**TABLE 3 |** Mean difference in EPDS scores according to postpartum practice experience and adherence<sup>a</sup>.

Postpartum practices	Difference in EPDS scores			
	Model1 <sup>b</sup>	(95% CI)	Model2 <sup>c</sup>	(95% CI)
<b>Satisfaction with experience<sup>d</sup></b>				
High rating (4–5)	0.00	(Reference)	/	
Not bad (3)	2.07	(1.28, 2.86)	/	
Low rating (1–2)	4.35	(3.49, 5.21)	/	
<b>Overall adherence<sup>e</sup></b>				
High adherence (18–30)	0.00	(Reference)	/	
Moderate adherence (14–17)	1.07	(0.20, 1.94)	/	
Low adherence (0–13)	1.72	(0.84, 2.60)	/	
<b>Restriction on diet</b>				
High adherence (7–9)	0.00	(Reference)	0.00	(Reference)
Moderate adherence (5–6)	0.17	(–0.78, 1.12)	0.15	(–0.81, 1.12)
Low adherence (0–4)	0.17	(–0.78, 1.12)	–0.41	(–1.42, 0.59)
<b>Restriction on housework-related and social activity</b>				
High adherence (9–14)	0.00	(Reference)	0.00	(Reference)
Moderate adherence (7–8)	1.02	(0.10, 1.94)	1.29	(0.35, 2.24)
Low adherence (0–6)	2.95	(2.11, 3.78)	3.43	(2.48, 4.39)
<b>Restriction on personal hygiene</b>				
High adherence (2–4)	0.00	(Reference)	0.00	(Reference)
Moderate adherence (1)	0.73	(–0.31, 1.76)	–0.17	(–1.22, 0.87)
Low adherence (0)	–0.33	(–1.25, 0.59)	–1.37	(–2.38, –0.37)
<b>Restriction on cold contact</b>				
High adherence (3)	0.00	(Reference)	0.00	(Reference)
Moderate adherence (2)	0.37	(–0.46, 1.21)	0.04	(–0.89, 0.81)
Low adherence (0–1)	0.99	(0.09, 1.88)	0.04	(–0.96, 1.04)

<sup>a</sup>Multiple linear regression was used to estimate the mean difference in EPDS scores.

<sup>b</sup>Model1 adjusted for education level (under bachelor, bachelor/graduate), planned pregnancy (yes, no), family history of postpartum depression (yes, no), depression diagnosis before pregnancy (yes, no), primary caregiver during 1-month postpartum (own mother, mother-in-law, husband/self, all others), recruitment location (Hunan provincial maternal and child health care hospital in Changsha, any other clinic).

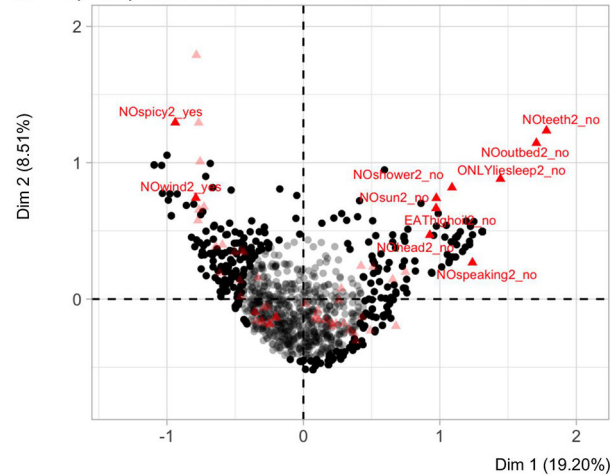
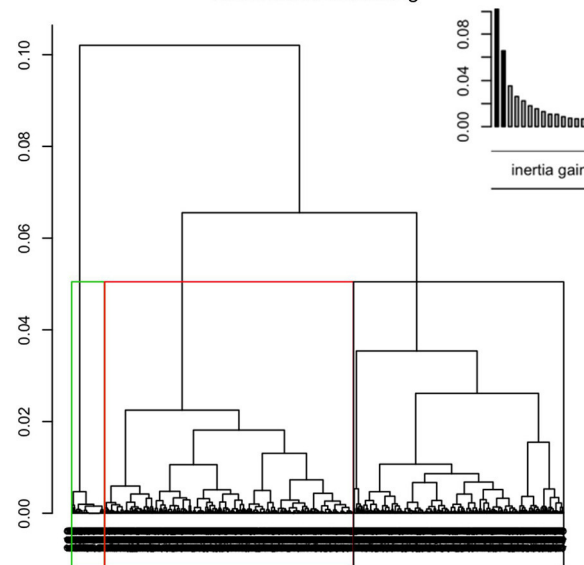
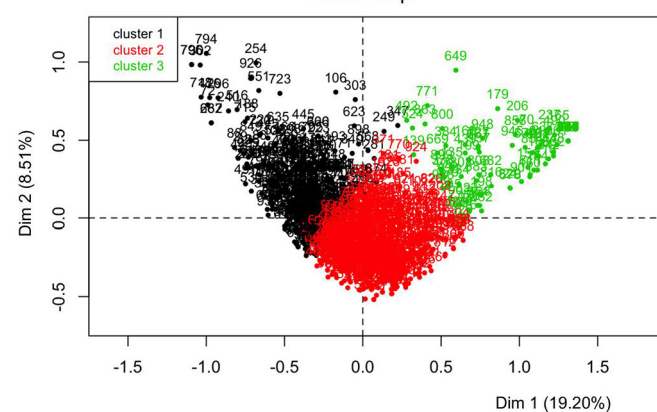
<sup>c</sup>Model2 additionally mutually adjusted other practice domains based on Model1.

<sup>d</sup>Scores ranged from 1 (least satisfactory) to 5 (most satisfactory).

<sup>e</sup>Adherence was determined by number of completed items.

with postpartum practices during a heightened sensitive period for depression occurrence. However, these mechanisms would require confirmations in longitudinal research. Indeed, our study has shown a mismatch between expectation and reality: most women would conduct traditional postpartum practices, but less than 20% expressed complete satisfaction toward their own “doing-the-month” experiences. A study in Beijing, China reported 55% (178/327) perceived “doing-the-month” useful (38), which is not an overwhelming victory as well. Moreover, women who considered “doing-the-month” as unhelpful showed twice the odds of PPD (38, 49). A Taiwanese study found complete dissatisfaction with instrumental support was very strongly positively correlated with EPDS scores in postpartum women, and women with a greater level of social support displayed fewer depressive symptoms (34, 50). The findings strengthen the conjecture that the demand for quality postpartum care is still unmet, and inadequate support may influence completion of postpartum practices, leading to stress or even depression (34, 39).

On one hand, low-adherence-related psychosocial stress may affect PPD development. Sources of stress include financial stress (51), family conflicts, and concerns on against “doing-the-month” as a social norm (39, 52). In other words, failed expectations in conducting interested practices may raise a concern of future health or add tension to the family relationship (22, 53), also refusal toward traditions may cause psychological stress and family conflicts (7, 38). For example, forced low adherence to the activity domain may be linked with the stress of returning to work for a living (51, 54) or insufficient maternal and paternity leave (55). A most recent prospective cohort study in Shanghai, China reported that women who left their homes during the first month postpartum could have at least 90% higher risks of PPD compared with those who never went outside (15). Additionally, traditional Chinese postpartum practices generally do not encourage exercises/workouts in this period (7), but limiting housework and exercises may have a different impact on mental status. Evidence-based guidelines are warranted to fill the blanks in traditional Chinese

**A** Top 1/3 practices and 1/3 individuals with most contribution in MCA**B** Hierarchical Clustering**C** Factor Map

**FIGURE 1 |** Hierarchical clustering on principle components (HCPC) for postpartum practices among postpartum women in Hunan, China, 2018–2019 ( $n = 955$ ). **(A)** Top 1/3 practices and top 1/3 individuals with most contribution in multiple correspondence analysis (MCA). MCA retains information from the first converted 19 dimensions (principal components) in this study, which accounts for 80% of information of the original 30 postpartum practices. The first two dimensions in MCA accounts for 19.20 and 8.51% information,

(Continued)

**FIGURE 1 |** respectively. On the plane formed by the first two dimensions, the dark black points denote 318 out of 955 individuals with most contribution in MCA results. The bright red triangles denote 10 out of 30 postpartum practices with most contribution in MCA results, including avoiding spicy and "hot" food, not brushing teeth, avoiding getting out of bed etc. **(B)** Dendrograms of hierarchical clustering on 19 MCA dimensions. Bar plots above dendrograms explain the gain of within-cluster inertia for each dendrogram, which assist in determining the levels at which the hierarchical tree was cut for clustering. The number of clusters were determined when no significant difference in between-/within-cluster inertia could be detected after adding/subtracting one more cluster. **(C)** Clusters are shown on two-dimension MCA factor map: Cluster 1 (343/955) denotes cluster with few items adhered, Cluster 2 (516/955) denotes cluster with mixed items adhered, and Cluster 3 (96/955) denotes cluster with most items adhered. There are no units for this type of graph since the principal component has no units.

postpartum practices (56), and to confront disagreement on postpartum exercises.

On the other hand, postpartum practices possibly contain protective elements to postpartum physical and mental relief (5, 6, 57). Satisfactory practical support could be an important element. Housework-related and social activity restrictions mainly represented the possible protective role of "doing-the-month" on preventing PPD in our study. For example, a study among 341 Taiwan women reported squatting as a predictor of high anxiety and depression scores in 2015 (58). This suggests that practical support on works requiring long-time standing/squatting or heavy lifting for postpartum women may offer some protective efforts. Notably, how women mentally perceive housework (54) or even how they evaluate received support may also affect their mental status (38, 49). In most families, practical support usually includes a caregiver(s) to free the mother from domestic housework duties (38). As our study shows more than 70% of primary caregivers were family members, satisfactory practical support from families might also reinforce family bonds and benefit mental health. Thus, limiting housework and social activities might provide considerable rest for physical recovery and mental wellness (4, 59). A prospective cohort study found that women who slept <6 h per night were twice more likely to suffer from PPD compared with those who slept 8 h (15). In this way, satisfactory practical support to new mothers after birth can be critical to maintaining subsequent self-esteem and wellness (4, 22).

In addition, mother-in-law as a caregiver used to be identified as a risk factor for PPD (4), conversely for own mother as a key helper (34). But there is no strong evidence of effect modification of primary care-givers in associations between postpartum practices and PPD in our study. The content and quality of postpartum support should receive more attention. To overcome disagreement from inter-generational beliefs and cultural taboos about postpartum activities, it is suggested to prepare a care team and detailed postpartum care plans beforehand, including housework distribution (1). As nearly half of postpartum women were following guidance from parents or parents-in-law, future health education on postpartum recovery should consider the family as a whole (39). This may serve to reduce psychosocial stress and improve practical support for the prevention of PPD.

For the relatively inconsistent evidence in restrictions on personal hygiene and cold contact, more replications are needed to explore their associations with PPD. The health belief model (60, 61) might be helpful to explain the degrees of adherence to postpartum practices, and the related mental health effects. Briefly, future investigations on adherence to postpartum practices might also want to evaluate how women perceive the susceptibility to complications of childbirth, the health benefits of

**TABLE 4 |** Mean difference in EPDS scores according to postpartum practice cluster patterns<sup>a</sup>.

Postpartum practice cluster	Difference in EPDS scores	
	Model1 <sup>b</sup>	(95% CI)
Cluster 3 (most items adhered)	0.15	(−1.11, 1.42)
Cluster 2 (mixed items adhered)	0.00	(Reference)
Cluster 1 (few items adhered)	1.72	(0.95, 2.48)

<sup>a</sup>Multiple linear regression was used to estimate the mean difference in EPDS scores.

<sup>b</sup>Model1 adjusted for education level (under bachelor, bachelor/graduate), planned pregnancy (yes, no), family history of postpartum depression (yes, no), depression diagnosis before pregnancy (yes, no), primary caregiver during 1-month postpartum (own mother, mother-in-law, husband/self, all others), recruitment location (Hunan provincial maternal and child health care hospital in Changsha, any other clinic).

these restrictions together with the received support, the barriers to adherence (52, 54).

## Strengths

Briefly, our study not only investigated overall adherence to "doing-the-month" or several behavioral items, but also analyzed postpartum practices by comprehensive domains and items. We found adherence to traditional postpartum practices differed by domain and by item, along with their relationships with PPD. This heterogeneity related to adherence indicates that "doing-the-month" remains a common but unstandardized custom (7, 8). Thus, via analyses of overall adherence and further break-down, on the one hand, our findings could probably capture the consistent relationship between adherence to traditional postpartum practices and PPD. On the other hand, as postpartum practices are observed globally, and western cultures generally have women navigate the postpartum transition independently (1, 2), this Chinese study might provide an informative reference for prevention or early intervention for mental disorder in the perinatal period in Chinese and other populations. Moreover, our study had a large sample size (~1,000 participants) and controlled for many important confounders in multiple regression, while some of the limited studies about adherence to postpartum practices and PPD (~200 participants) used correlation analyses (22). Finally, to our best of knowledge, this study is one of the few studies investigating the impact of housework-related restrictions on postpartum mental health (54).

## Limitations

Nevertheless, this cross-sectional study has several limitations. First, postpartum women were only contacted after 1-month confinement, and less healthy individuals were less likely to be enrolled or to finish the questionnaires. Secondly, most of the participants were sampled from the provincial hospital with



higher education and income level than average, which might limit the external validity of the findings. But the recruitment location was adjusted and did not show significant effect modification. In addition, the modified version of PDQ has not been validated in our study. However, since our revision was based on feedback from the participants in our pilot survey, it is less likely to threaten the validity. Also, we did not obtain information on life events stress in the perinatal period which might be a risk factor of PPD. But one of the most common sources of perinatal stress is financial stress, and the results where we additionally adjusted for household income did not significantly change. Additionally, there was no clinical assessment to evaluate biological changes and physical conditions including hormone levels or sleep quality other than mental health screening. Finally, reverse causality and confounding cannot be ruled out as explanations, as depressive symptoms which began before childbirth might account for a portion of PPD identified, and could act as a confounding in the practice-PPD pathway and could in turn alter postpartum physical and social activeness. But first, we adjusted family history of PPD and diagnosis of depression before pregnancy, second, the screening time in our study was just about the typical onset timing of PPD [symptoms begin within 6 weeks postpartum in 80% of cases] (6). Future studies may employ repeated assessments at shorter intervals throughout the perinatal period to identify onset timing of depressive symptoms (62), also for early prevention.

## CONCLUSIONS

In conclusion, "doing-the-month" remains a common but heterogeneous custom for postpartum women. Overall low adherence to the traditional Chinese postpartum practices was associated with higher EPDS scores indicating PPD symptoms, especially in the domain of housework-related and social activity restrictions. Psychosocial stress and unsatisfactory practical support related to low adherence to postpartum practices might contribute to PPD. The protective elements within Chinese postpartum practices might gain valuable insights into prevention or early intervention for mental disorder in the perinatal period in Chinese and other populations. Longitudinal study and clinical assessment of PPD would be needed to further explore the health impacts of adherence to multifaceted domains of postpartum practices considering the biopsychosocial approach.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by The ethical review committee of Xiangya

School of Public Health Central South University. The patients/participants provided their written informed consent to participate in this study.

## AUTHOR CONTRIBUTIONS

PG: data analysis, methodology, writing original draft, reviewing, and editing. DX: conceptualization, methodology, writing original draft, reviewing, and editing. ZL: conceptualization, methodology, data analysis, reviewing, and editing. HH: conceptualization, methodology, and data analysis. PB and BT: conceptualization, reviewing, and editing. CZ and XJ: data curation, investigation, methodology, and project administration. WG: conceptualization, funding acquisition, investigation, methodology, project administration, resources, supervision, reviewing, and editing. All authors contributed to the article and approved the submitted version.

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## SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpsy.2021.649972/full#supplementary-material>

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