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Insights in social psychiatry and psychiatric rehabilitation 2022

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Insights in social psychiatry and psychiatric rehabilitation: 2022

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Editorial: Insights in social psychiatry and psychiatric rehabilitation: 2022

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KEYWORDS

social psychiatry, mental health care, community care, co-production, rehabilitation

Editorial on the Research Topic
Insights in social psychiatry and psychiatric rehabilitation: 2022

The articles in this Research Topic beautifully capture some of the most important themes in modern mental health care, and indeed in healthcare generally. Through what is proving to be a most difficult decade so far for humanity generally, with prolonged, devastating and traumatic conflicts around the world, the importance of connection, social capital, and partnership in healthcare has continued to gain ground. Health care providers and those who use services working together to find new ways of treating and managing conditions, new ways of measuring outcome, and indeed new ways of defining what 'success' or recovery looks like are very welcome indeed.

This Research Topic of very different articles has human experience and innovation as it's common strand. The authors come at the problem from very different angles, and all give us useful insights in different areas and using a variety of methods. Chirio-Espitalier et al. explore the recovery construct in bipolar disorder as defined by personal rather than clinical or functional perspectives, concluding with numerous suggestions for further research and the refinement of practice. Lakshman et al. in Malaysia tested a Malay language version of a tool for assessing recovery orientated knowledge amongst health staff. They concluded that an adapted short version showed higher levels of validity and reliability- a real win as it will be easier to use in large scale studies and clinical practice. von Peter et al. reported on their co- produced instrument for measuring fulfilment of needs and experiences in psychiatric treatment (NEPT), in what was a striking example of career researchers and experts by experience working alongside each other. With many mental health scandals still occurring around the world, both in institutions and in the community, such collaborations could and should play a crucial part in ensuring that what is measured (and thus monitored) is appropriate and patient centred. Leading on from this, Umucu et al. reported on their fascinating and important work analysing so-called 'character strengths' in large groups of people with different disabilities. They received detailed responses from nearly 12,000 people across more than twelve countries and found the top five strengths were love of learning, honesty, appreciation of beauty and excellence, kindness, and fairness. What wonderful blocks to build on when helping people move forward in their lives and a real foundation for empowering and strengths-based services! Their more detailed findings should help those developing rehabilitation pathways for different conditions to focus on areas of strength that can be utilised and built upon, hopefully leading to better experiences of care and better outcomes in time.

Several of the other papers in the Research Topic remind us just how important our overall environment is and of the significant challenges that people with mental health problems can face. Wu et al. reported high rates of PTSD (over 13%) in a population affected by natural disaster, in this case a tornado. These kinds of damaging weather events are already becoming more common and more destructive, and no doubt rates of psychological trauma will rise in step with this, especially in parts of the world that are most affected. Reporting from China also, Chen et al. eloquently describe the twin effects of severe mental illness and homelessness and the inequalities that can lead to the latter, such as having lower levels of education and/or being from a minority group. Cheng and Lai examine another important issue with a systematic review of stress in the parents of children with special educational needs, finding that challenging behaviour, financial stress, and social isolation all contribute to negative feelings. Conversely good professional support and positive relationships are helpful and protective.

The final three papers in the Research Topic all look at possible ways forward. Asher et al. conducted detailed interviews with people taking psychotropic medication and describe complex interacting themes around feelings, beliefs, and emotions that are important for medication compliance and that are useful to understand when prescribing. Hug et al. conducted research among psychiatric inpatients, with many reporting that work and education were not addressed with enough priority by the treating team. 76% of those asked expressed a need for support, with 92% of those asking for job coaching. Finally, Tan et al. developed and piloted a gamified augmented reality approach to vocational skills in people with learning disabilities and found encouraging results and excellent tolerability.

The span of these Research Topic shows just how vibrant social psychiatry remains and how crucial it is to the human condition and to attempts to improve the quality of life of those affected by mental health problems.

Author contributions

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Editorial: Insights in social psychiatry and psychiatric rehabilitation: 2022: Foreword

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Editorial on the Research Topic
Insights in social psychiatry and psychiatric rehabilitation: 2022: Foreword

This Research Topic presents insightful results on different topics in the field of Social Psychiatry and Psychiatric Rehabilitation, including the role of recovery assessment, the need to promote social/work support, to improve quality of life through recovery-oriented programs, the needs of highly disadvantaged patient population, and the need to expand shared-decision making actions in psychiatry and psychosocial rehabilitation.

Considering advancement in assessing the recovery process, insights come from von Peter et al. and Lakshman et al. The formers presented initial results on the development of a new research tool, the *Needs and Experiences in Psychiatric Treatment (NEPT*), to evaluate the experiences and fulfillment of needs during psychiatric treatment from the perspective of users. This tool was developed during a participatory-collaborative process evaluation from controlled, multi-center, prospective cohort study, aiming at evaluating psychiatric Flexible and Integrative Treatment models. The research team consisted of researchers with and without experiential expertise. As NEPT showed good psychometric properties, NEPT was considered a promising tool for further development to assess the experiences and fulfillment of needs of psychiatric care models from a user's perspective. Lakshman et al. developed a Malay-language version of the *Recovery Knowledge Inventory*, one of the most influential scales to assess knowledge and attitudes toward recovery-oriented practices among mental health providers. The study demonstrated that, while the original 20-item scale did not exhibit sufficient validity among Malaysian mental health workers, the modified 11-item Malay-version had good construct validity for application in clinical practice.

Then, results from systematic reviews come from Chirio-Espitalier et al. and Cheng and Lai. Considering that Personal Recovery (PR) is an important mental health goal, Chirio-Espitalier et al. conducted a systematic review on 24 papers evaluating PR in bipolar disorder (BD) patients: it was found that, while PR did not closely correlate with symptomatology, some elements of PR differ between BD patients and patients with other severe mental illness (SMI). Moreover, as the role of caregiver, communication modalities within care and knowledge gained from peers were equally important, the authors suggested that these elements should be more broadly considered to improve recovery-focused care in BD. Subsequently, through a systematic review on 26 papers, Cheng and Lai identified the risk and protective factors for parental stress in families with children with special educational needs: as several risk and protective factors were found, it was suggested to design actions at social and mental health level to promote the wellbeing of parents at high risk of developing disabling mental conditions.

The topic of social support and quality of life was evaluated in chronically homeless patients (HP) with schizophrenia: Chen et al. provided results on 3.967 HP and 3.724 non-homeless patients (NHP) in rural China. As sociodemographic differences between groups emerged,the study established that HP, compared to NHP, showed lower scores at the *Social Support Rating Scale*, confirming that HP were unlikely to obtain social support. Furthermore, HP experienced more anxiety, depression, physical pain, reduced quality of life and were characterized by increased psychoticism and neuroticism, indicating also higher levels of antisocial behavior and emotional distress.

The role of social policies in facilitating access to mental health services is also addressed in Wu et al. who analyzed the effects a major natural disaster on the development of disabling mental disorders: the authors evaluated prevalence and symptoms of PTSD in a group of survivors after a tornado disaster: on 237 survivors, 13.6% of the sample was diagnosed with PTSD. Furthermore, being female and having suffered from severe property damage, increased the risk of developing PTSD. As nearly two-thirds of PTSD individuals did not seek mental assistance, due to stigma and lack of knowledge about psychological assistance, it was suggested that, in case of exposure to natural disasters, social policies should increase accessibility to mental health services through specific awareness campaigns.

Considering the role of Positive psychology in emphasizing positive qualities, Umucu et al. provided results from an exploratory study illustrating the difference in *character strengths* on 11.699 subjects presenting with different types of disabilities. They demonstrated a differential distribution of the *character strengths* construct, suggesting that the evaluation of *character strengths* in people with disabilities could improve the implementation of tailored rehabilitative interventions.

Then, the topic of work support was evaluated by Tan et al. providing preliminary results on the acceptability and effectiveness of the *Augmented Reality Games to Enhance Vocational Ability of Patients (REAP*) program in 15 adults with intellectual and developmental disabilities attending work therapy. REAP programs consisted of gamified augmented reality café training scenarios and bridging group activities to facilitate transfer of learning to the work context. Results indicated that REAP programs were useful for most of the participants and trainers, providing unique opportunities to acquire new skills. Subsequently, Hug et al. assessed work-related impairments in participation and the need for support among 93 adult patients in day-care/inpatient setting. They found that 76% of the patients expressed a need for support, of which 92% expressed interest in job coaching. However, about half of the sample received support from the treatment team, suggesting that the need for support was insufficiently met. As work and training were highly relevant topic for people with SMI, it was suggested that appropriate measures to support work and professional employment are urgently needed to promote recovery.

In a shared-decision making perspective, to better understand the non-adherence phenomenon in individuals with SMI, Asher et al. studied the complex processes of developing attitudes toward medication and decisional aspects on their patterns of use. They found that these processes progressed through distinct sequential phases that are dynamic and non-linear, suggesting that clinicians have to evaluate these processes through a shared dialogue with the patient focusing on personal attitudes and beliefs regarding medications. By doing this, therapeutic alliance could be further implemented in a recovery-oriented care model.

Concluding, as recovery, quality of life and well-being are actual milestones of Social Psychiatry and Psychiatric Rehabilitation, we believe that, strengthening the evidence covered in this Research Topic, will bring to improve the value of psychosocial and recovery-oriented actions in patients with SMI.

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Needs and Experiences in Psychiatric Treatment (NEPT)- Piloting a Collaboratively Generated, Initial Research Tool to Evaluate Cross-Sectoral Mental Health Services

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Background: Research tools to evaluate institutions or interventions in the field of mental health have rarely been constructed by researchers with personal experience of using the mental health system ("experiential expertise"). This paper presents a preliminary tool that has been developed within a participatory-collaborative process evaluation as part of a controlled, multi-center, prospective cohort study (PsychCare) to evaluate psychiatric flexible and integrative treatment, FIT for short, models in Germany.

Method: The collaborative research team consisting of researchers with and without experiential expertise developed 12 experiential program components of FIT models by an iterative research process based on the Grounded Theory Methodology. These components were transformed into a preliminary research tool that was evaluated by a participatory expert panel, and during a pilot and validation study, the latter using a random sample of 327 users from 14 mental health departments. Internal consistency of the tool was tested using Cronbach's alpha. Construct validity was evaluated using a Principal Components Analysis (PCA) and a Jonckheere Terpstra test in relation to different implementation levels of the FIT model. Concurrent validity was tested against a German version of the Client Satisfaction Questionnaire (ZUF-8) using correlation analysis and a linear regression model.

Results: The evaluation of the expert panel reduced 29 initial items to 16 that were further reduced to 11 items during the pilot study, resulting into a research tool (Needs and Experiences in Psychiatric Treatment—NEPT) that demonstrated good internal consistency (Cronbach's alpha of 0.89). PCA yielded a 1-component structure, which accounted for 49% of the total variance supporting the unidimensional structure of the tool. The total NEPT score increased alongside the increasing implementation of the FIT model ($p < 0.05$). There was evidence ($p < 0.001$) for convergent validity assessed against the ZUF-8 as criterion measure.

Conclusions: The NEPT tool seems to be promising for further development to assess the experiences with and fulfillment of needs of psychiatric care models from the perspective of users. This paper demonstrates that it is possible to use a participatory-collaborative approach within the methodologically rigorous confines of a prospective, controlled research design.

Keywords: PREM, peer research, coproduction, collaboration, tokenism, experience, user involvement

INTRODUCTION

Research tools and psychometric scales used to evaluate institutions and interventions in the field of mental health have mostly been constructed by clinical scientists with no personal experience of the psychiatric care system, mental crises and disabilities or recovery from them (in the following designated as "experiential expertise"). Yet, there is a rich tradition of research and knowledge production by scholars with experiential expertise that has been contributing to the mental health field for more than two decades in various countries (1–4). Using different epistemological and theoretical approaches (5–8), these studies frequently articulate valid criticism toward the current medicalized approach to psychiatric care (2), the psy-centrism of contemporary social infrastructures (8), as well as the appropriation of contrasting perspectives and positions (1), resulting into the silencing of possible alternatives—also on the level of knowledge production.

Given this context, only a few research groups in the field of mental health, led by or including researchers with experiential expertise, have been able to establish. One of these exceptions is SURE (Service User Research Enterprise)/United Kingdom, hosting exclusively researchers with experiential expertise who investigate and evaluate various health care services using self-developed criteria, standards, and instruments (9). Developed by this group and others, several scales have been created by researchers with experiential expertise: As early as 1996, Diana Rose's hybrid team created the "CONTINU-UM scale" to evaluate the continuity of psychiatric treatment (10). In the following year, Rogers created the "Empowerment Scale," using expertise from a participatory board staffed by activists from self-help groups (11). The "Evans VOICE Inpatient Care Scale" was also developed in a participatory way and surveys the aspects of care that users consider to be important (12). The questionnaire about the process of recovery (QPR) was developed by a collaborative research team and may assist users to set treatment goas (13). The last example is the "CEO-MHS," for which researchers with experiential expertise created a questionnaire to record user satisfaction (14).

This paper presents the first steps of developing a novel research tool that aims at evaluating the experiences and fulfillment of needs during psychiatric treatment from the perspective of users. This tool was developed during a participatory-collaborative process evaluation as part of a controlled, multi-center, prospective cohort study (PsychCare), aiming at evaluating psychiatric, innovative, flexible, and integrative treatment (FIT) models in Germany (15). These FIT model projects are mainly hospital-based and enable a more need-adapted, cross-sectoral service delivery, including complex outpatient forms of psychiatric treatment (16). Our approach involved the continuous collaboration between researchers with and without experiential expertise with the psychiatric care system, crises and disabilities or recovery from them (17). It is based on a cooperation that neither intends to meet the strict and egalitarian criteria of co-production (18, 19), nor the systematic involvement of actors in the field under investigation, as practiced in participatory research projects (20). Instead, our mode of collaboration allowed to substantially build upon knowledge of researchers with experiential expertise within the methodologically rather rigorous confines of a prospective, controlled cohort study.

The overall aim of the PsychCare study was to examine the benefits, costs, and efficiency of more flexible, continuous, and setting-integrated treatment models in Germany in comparison to standard care currently provided. Following the MRC Guidelines for the Evaluation of Complex Evaluations (21), one part of this study included a participatory process evaluation that was realized by the mentioned collaborative teamwork. The main results of this process evaluation will be presented elsewhere (22). This paper focusses on the collaborative development of a research tool during this process evaluation that aimed at evaluating the experiences and fulfillment of needs during psychiatric treatment from the perspective of users. The construction of this research tool and the initial steps of piloting and validation will be described, followed by a discussion on its value within the context of this study and beyond.

MATERIALS AND METHODS

The PsychCare study is financed by the German Innovation Fund of the Federal Joint Committee (G-BA) (grant reference no. 01VSF16053), which invests resources from the health care insurance system in researching innovative health programs (23). The study is aimed at evaluating innovative psychiatric treatment models that have gradually been developed following the 2012 introduction of the § 64b of the German Social Code Book V (22). Results of previous studies on this topic are published elsewhere (16, 21, 22, 24–29). The above-mentioned law enables the implementation of more flexible and integrative, psychiatric treatment models (FIT models) based on a Global Treatment Budget (GTB). Given the rather rigid and fragmented nature of the German health care system, these FIT models allow for more user-oriented and outpatient forms of treatments (30). As a result, users stay mainly in their home environment but can also be treated flexibly in the clinic with less bureaucratic hurdles. Ideally, this allows better integration of the treatment into the user's everyday life and a better insight into their reality of life by the staff (31).

The aforementioned GTB targets a fixed number of people to be treated per year. How this budget is used, for which treatment, in which settings and for what purpose is decided by the relevant institution. A total of 22 of these FIT models can currently be found in the hospital sector in Germany.

Team Structure and Cooperation

The results presented in this manuscript build on a previous study, Eva-Mod64 (22), in which 13 FIT hospital departments were evaluated between 2016 and 2017, resulting into the development of 11 process and structure-related program components of FIT models (16, 22, 24). Whereas this precursor study was carried out only by researchers without experiential expertise, the team of the PsychCare participatory process evaluation was staffed by both researchers with (in the following "experiential experts," EE) and without experiential expertise ("conventional researchers," CR). This team composition was chosen to direct the evaluative focus on the specific experiences of FIT model users. The three EE involved in the team were researchers with and without academic degrees. The CR group consisted of two medical students, two paid researchers and the team principal, the latter working in psychiatry but not having personal experiences as mental health service users.

The team met as a whole or in subgroups (CR only, EE only, or EE + CR). In between meetings, the team members worked individually, alone or in tandems, consisting of one EE and one CR each. In addition, supervision sessions took place three times per year, covering the whole group or CR and EE as individual groups. During these supervisory sessions, the collaborative approach and its impact on the research results were reflected upon. The results of this work will be published elsewhere (32). The whole team contributed to all phases of this project, and also as authors of this paper.

Construction of the NEPT Research Tool

The construction of the NEPT research tool was carried out in several steps shown in **Figure 1** to reduce complexity. Chapter 2.2 describes the construction of the experiential components and the preliminary items of the NEPT research tool. An ethics vote of the TU Dresden dated 07.09.2017 was available.

Construction of the Experiential Components

At the beginning of the study, the 15 core transcripts containing focus group material from the EvaMod64b precursor study (25) were re-coded to familiarize the team with the research topic. An evaluation method based on Grounded Theory Methodology (GTM) (33) was chosen, as the GTM allows for the systematic inclusion of various positions and forms of knowledge during a coding process, a high degree of process orientation and flexibility, and the systematic handling of conflicting perspectives and irritations (31). The coding of these transcripts was carried out in tandems of EE and CR using a computer assisted qualitative data analysis software *NVivo* (34) and the 11 process- and structure-related components of the precursor study as deductive categories (26). While the CR coded deductively, the EE were encouraged to add open codes, which enabled them to systematically feed personal experiences and/or collectivized forms of experiential knowledge into the coding process.

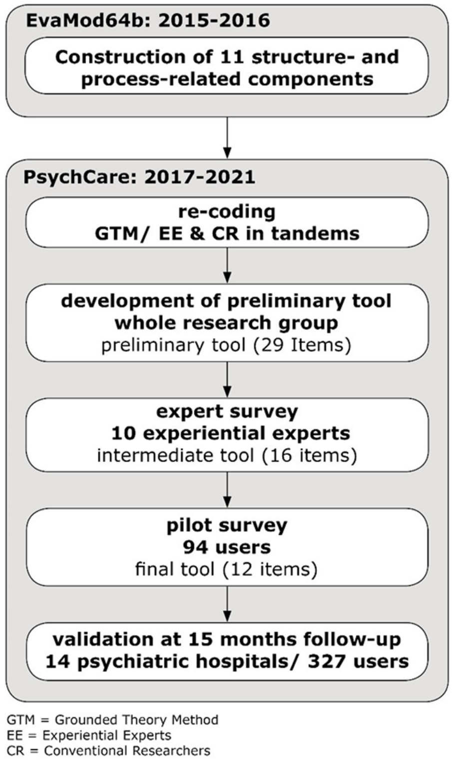
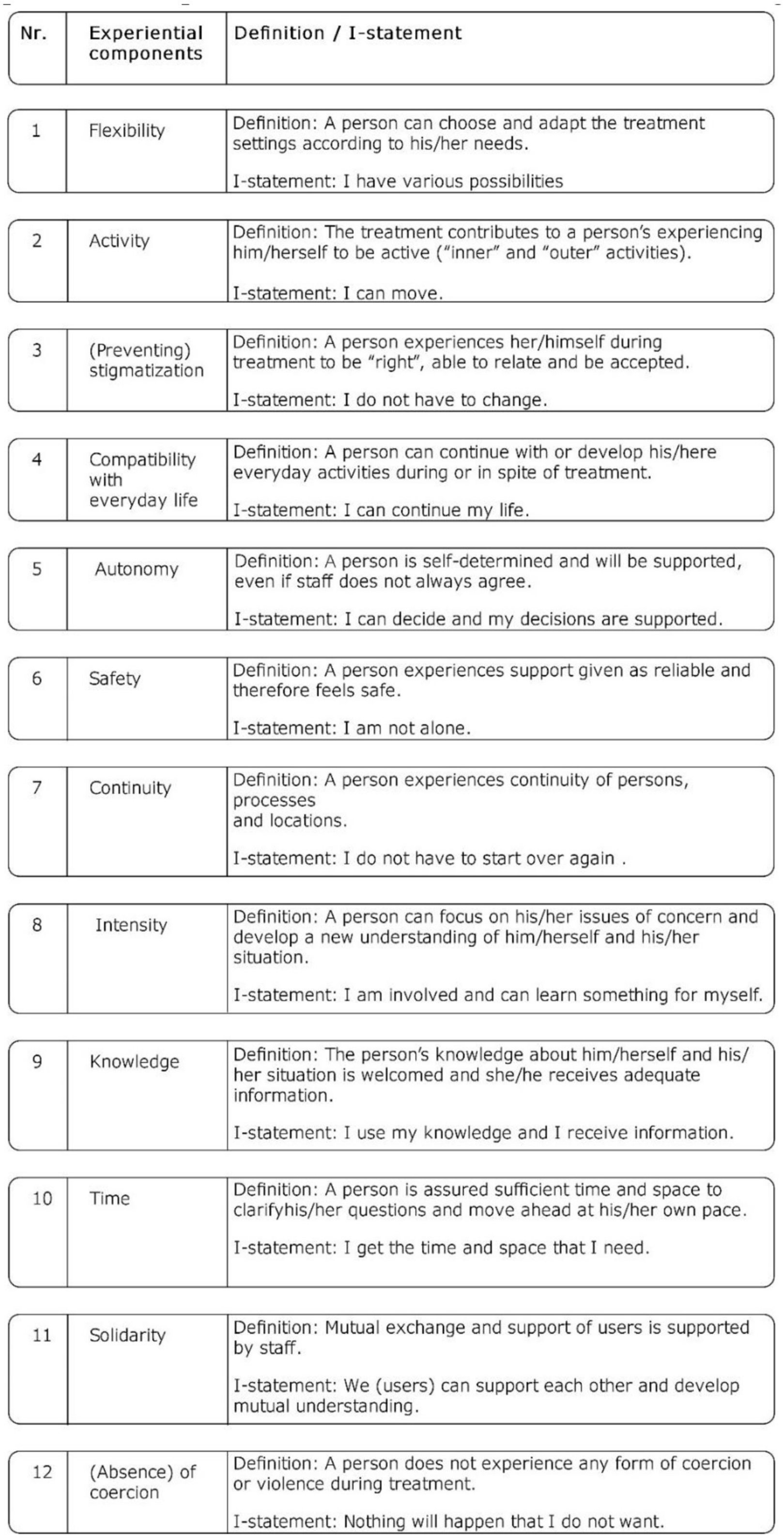


FIGURE 1 | Multi-step, collaborative construction of the NEPT research tool.

This process enabled "creative chaos" (30) allowing the group to discover and code new aspects and to open-up the possibility of systematically enriching the insights from the precursor study through experiential expertise and generalizing them further (22). As a result, a set of 12 so-called experiential program components emerged (**Figure 2**), aiming at capturing the experience of the FIT model users. As these components emerged from the coding process described above and the underlying experiential knowledge of the EE involved, they were framed as "I-sentences" to highlight their experiential character. They were further defined, repeatedly discussed, and finally agreed upon by the whole group and, in accordance with GTM, systematically linked to each other, as well as to the process and structure-related components of the precursor study.

Construction of the Questionnaire Items

The experiential components served as a theoretical basis to develop the research guidelines for the qualitative part of the



Nr.	Experiential components	Definition / I-statement
1	Flexibility	Definition: A person can choose and adapt the treatment settings according to his/her needs. I-statement: I have various possibilities
2	Activity	Definition: The treatment contributes to a person's experiencing him/herself to be active ("inner" and "outer" activities). I-statement: I can move.
3	(Preventing) stigmatization	Definition: A person experiences her/himself during treatment to be "right", able to relate and be accepted. I-statement: I do not have to change.
4	Compatibility with everyday life	Definition: A person can continue with or develop his/here everyday activities during or in spite of treatment. I-statement: I can continue my life.
5	Autonomy	Definition: A person is self-determined and will be supported, even if staff does not always agree. I-statement: I can decide and my decisions are supported.
6	Safety	Definition: A person experiences support given as reliable and therefore feels safe. I-statement: I am not alone.
7	Continuity	Definition: A person experiences continuity of persons, processes and locations. I-statement: I do not have to start over again .
8	Intensity	Definition: A person can focus on his/her issues of concern and develop a new understanding of him/herself and his/her situation. I-statement: I am involved and can learn something for myself.
9	Knowledge	Definition: The person's knowledge about him/herself and his/her situation is welcomed and she/he receives adequate information. I-statement: I use my knowledge and I receive information.
10	Time	Definition: A person is assured sufficient time and space to clarifyhis/her questions and move ahead at his/her own pace. I-statement: I get the time and space that I need.
11	Solidarity	Definition: Mutual exchange and support of users is supported by staff. I-statement: We (users) can support each other and develop mutual understanding.
12	(Absence) of coercion	Definition: A person does not experience any form of coercion or violence during treatment. I-statement: Nothing will happen that I do not want.

FIGURE 2 | The developed 12 experiential components that reflect the experiences and fulfillment of needs of psychiatric treatment from the perspective of service users. To this end, they were framed as I-statements and their definitions were given accordingly.

process evaluation (35). They were further used to construct items of a standardized research tool that assesses the experiences with and fulfillment of needs of the evaluated care models from the perspective of users. This tool was introduced during the 15 months follow-up of the PsychCare study's outcome evaluation to assess the experiences of a larger number of users in a more standardized way (15), to be able to triangulate the results of the study's process with those of the outcome evaluation. A second aim was to better understand the value of an evaluative construct to assess user experiences, and in how far such construct may share similarities with other constructs, for example to evaluate treatment satisfaction. Literature on this question usually targets PREM constructs (patient reported experiential measures) (36, 37), however generally not involving experiential expertise during their processes of construction.

To this end, the experiential components were transformed in several stages into questionnaire items that ultimately resulted in a questionnaire called "Needs and Experiences in Psychiatric Treatment" (NEPT). The first stage consisted in converting the I-sentences of the components into questions by the EE subgroup. These questions were discussed and further developed into 2 or 3 different questions per item by the whole group. The component "*Flexibility*" (see **Figure 2**), for instance, was assigned to the questions: "Were you treated overall in the settings that were suitable for you (full-time inpatient, day clinic, at home)" and "Did the change between the settings take place in a way that was suitable for you?." To facilitate understanding and to do justice to their experiential nature, all questions selected were then re-converted into I-statements that, finally, were endued with a five-level Likert scale (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree).

Piloting the NEPT Research Tool

After developing the questionnaire items (s. 2.2), they were piloted and validated. This took place in three surveys, first in an expert survey, then in a pilot survey and finally using a larger population during the 15 months follow-up of the PsychCare study's outcome evaluation.

Expert Survey

The content validity of the questionnaire items was calculated using an expert panel (38). The expert survey targeted a group of 10 EEs, also deviating from the precursor study, in which only CR had undertaken this phase of the validation process (21). For this expert survey, the group consisted of users, mental health activists, patient representatives, recovery companions and peer and user researchers, with the majority of these experts having several of these identities. Overall, women predominated in the group (7:3), members ranged in age from 26 to 72 years.

The preliminary items were presented in two rounds to the expert group that was asked to assess which of the assigned questions best captured the essence of the underlying components. A rating from 1 to 3 was given, 1 standing for "essential," 2 for "appropriate but not essential" and 3 for "not essential." At least half of the experts had to agree that a question should be classified as "essential" to confirm its content validity (3). Based on the results of this expert survey, a scale with five levels of "not at all applicable," "somewhat inapplicable ," "neutral," "somewhat applicable " and "fully applicable" was assigned, which served to evaluate the items during the pilot survey.

Based on the results of the expert assessment, the final questionnaire was developed, which contained a total of 16 items, assigned to the 12 experiential components on which it was based.

Pilot Survey

The pilot survey included 94 users of one of the FIT model departments that was not included in the main study, with the sample drawn from three treatment settings (outpatient clinic, day clinic and hospital ward) according to a quota principle. Respondents were asked to rate the items using the above-mentioned five-point scale. In addition, the respondents' detailed comments on individual items were recorded.

Based on the feedback of the participants, the correlations and reliability of the items were determined. With reference to previous studies (39), in which socially desirable response behavior was shown to occur in the evaluation of health care services, the items were coded as follows: "not at all applicable" to "neutral" = 0, "somewhat applicable" = 1 and "fully applicable" = 2. Further, selection of items on the questionnaire was based on the principle of excluding items with low internal consistency with the scale, the cut off for dripping items being set at ≤ 0.7. This strategy, called alpha maximization (38), was used with the greatest caution, as it can lead to the elimination of items with low selectivity, necessary to distinguish all areas of the dimensional spectrum. In addition, this strategy can lead to a reduction of content validity, which is why the research team also took content considerations into account when selecting the items (40).

Validation of the NEPT Research Tool

The developed NEPT questionnaire was handed out to the investigated users of the 15 months follow-up of the PsychCare outcome evaluation. For details on inclusion and exclusion criteria see Soltmann et al., (15). Socio-demographic characteristics of the sample were assessed using descriptive statistics.

Testing Internal Consistency

The internal consistency of the NEPT tool was assessed by estimating item–total correlations by Spearman's rank, which expresses the degree to which the items of an instrument are measuring the same attribute. Additionally, the correlation matrix was checked. The size of the correlations was based on the following interpretation limits according to Cohen (41): $0.10 > r < 0.30$, small effect size; $0.30 > r < 0.50$, medium effect size and $r > 0.50$, large effect size. Internal consistency was also estimated using a Cronbach's alpha reliability coefficient. A Cronbach's $\alpha > 0.6$ and ≤ 0.7 was considered an acceptable value; a value >0.7 and <0.9 a good value; and a value of 0.9 or higher indicated excellent reliability (42). For the pilot testing, alpha maximization was used as a criterion for item elimination; the cut off for dropping items was 0.7.

Testing Validity

Validity was assessed in several ways: First, an exploratory Principal Components Analysis (PCA) was conducted to evaluate the underlying structure of the instrument (43). To test for the adequacy of PCA, we used the Kaiser-Meyer-Olkin measure (should be $\geq$ 0.5) (ibid) and the Bartlett test of sphericity (ibid) (should be significant). A strict cut-off of factor loading of $>$ 0.50, used by other researchers (44) was adopted. This method is primarily used to explore covariation without having a prior hypothesis or theory (45). In our case, the number of components to extract were based on three criteria: the Eigenvalue >1 (Kaiser), the Velicer MAP criterion (Polychoric correlations), and the Velicer MAP criterion/ 4th power (46, 47) using simulated polychoric correlation matrices.

In a second step and to support construct validity, known-groups validity was examined, testing hypothesized groupings of the survey outcomes, and detecting differences between them (48). A linear trend was tested across participants from three mental health hospital groups with different health care providing levels (centers providing standard health care, centers providing both FIT and standard treatment, and centers exclusively providing FIT treatment), using the Jonckheere-Terpstra test, one-tailed from a Monte Carlo simulation (10 000 samples) (49). The hypothesis was that these groups were ordered in a specific sequence, expecting that the participants from the hospital groups with a higher level of the FIT treatment would have higher NEPT total scores.

Third, concurrent validity was assessed by comparing the total NEPT scores with the total ZUF-8 scores (50), a German version of the Client Satisfaction Questionnaire CSQ-8 (51) that was also used at the 15 months follow-up of the PsychCare study. Concurrent validity was analyzed both by calculating a Pearson's correlation (38) and by using a multiple linear regression model, adjusted for the influence of the two demographic covariates gender and age. Missing data of NEPT and ZUF-8 questionnaires were not imputed. The size of the Coefficient of determination (R^2) was based on the following interpretation limits according to Cohen: $R^2 < 0.02$—very weak, $0.02 \leq R^2 < 0.13$—weak, $0.13 \leq R^2 < 0.26$—moderate, $R^2 \geq 0.26$—substantial (52). We expected to find a significant correlation with a large effect size between ZUF-8 total and the NEPT total-scores using correlation analysis and a significant association with a substantial R^2 in a linear regression analysis with the NEPT total value as a dependent and the ZUF-8 total as an independent variable.

The significance level was set at $p \leq 0.05$. Most analyses were performed with the Statistical Package for Social Sciences (SPSS), version 23.0 for Windows. The Velicer MAP criterion and the Velicer MAP criterion/4th power were examined with the *r* package "random.polychor.pa" running in *r* version 4.0.5 (45).

RESULTS

Cooperation Within the Group

A detailed description of the teams' collaborating processes and experiences while conducting this study has been published elsewhere (32). As described above, staffing the team with a mix of researchers with and without experiential expertise, organizing our work in different sub-groups and tandems, made it possible to systematically incorporate experiential expertise throughout the whole research process. It opened-up an "area of negotiating meaning and representation" (53), enabling new forms of knowledge and the recombination of different forms of knowledge to evaluate and (hopefully) ultimately improve psychiatric treatment.

At the same time, the research group was located within a privileged site of knowledge production (university) and entrenched within the confines of a rather traditional research design (prospective, controlled study). Thus, collaborative knowledge production was subject to various contingencies, emerging from academic rules and parameters that also defined to a certain extent the roles and responsibilities of the researchers involved. This led to a rather disciplined form of experiential expertise coming into play, that stretched the standard criteria of health service research and/or psychiatric discourse but ended up subjugating its emancipatory potential to the authority of scientific knowledge and academic knowledge production. Longstanding, structural inequalities of university knowledge production as well as rather strict (mental) health service research epistemologies remained largely untouched, leading to various frustrations especially on the side of the researchers with experiential expertise [for further details see Beeker et al. (32)].

Construction of the NEPT Research Tool

Construction of the Experiential Components

Over the course of the construction process, 12 experiential components were developed based primarily on the knowledge of the researchers with experiential expertise. The differences between these experiential components and the set of process and structure-related components from the precursor project, and the role that experiential knowledge played in producing them, will be described elsewhere (22). At this point, it is sufficient to point out that the collaboration between researchers with and without experiential expertise resulted in (1) a number of new components with new areas of content, (2) the re-definition and/or -operationalization of the previous components, in some cases considerably, and (3) further generalization of these experiential components, transcending their original evaluative focus on FIT models to move toward the evaluation of "good psychiatric care" (see Discussion Section). A compilation of the 12 experiential components and their definitions can be found in **Figure 2**.

Construction of Questionnaire Items

A total of 29 survey items were developed in several steps, with 2-3 items assigned to each of the experiential components. The items were listed and can be found in the accessory material to this manuscript (**Supplementary Table A1**).

Piloting of the NEPT Research Tool

Results of the Expert Survey

In the expert survey, 16 out of the 29 survey items were rated "substantial" by at least half of the experts. Thereafter, the following number of items remained in the preliminary questionnaire: *Flexibility* = 1 item, *Activity* = 1 item, *Avoidance of stigmatization* = 1 item, *Compatibility* = 1 item, *Autonomy* = 2 items, *Safety* = 1 item, *Continuity* = 2 items, *Intensity* = 1 item, *Knowledge* = 2 items, *Time* = 1 item, *Solidarity* = 1 item, *Absence of coercion* = 2 items.

The remaining 13 items were eliminated. The main reasons for the low rating of eliminated items were that, according to experts, they did not sufficiently reflect the essential aspects of experience or were redundant, such as the items: "Switching between different settings went so well that it suited me" (eliminated due to redundancy), "I was supported in developing activities that were helpful to me" (eliminated as activity was not sufficiently specified), "The treatment conditions (behavior of personals, rooms, regulations) allowed me to look at myself benevolently" (elimination as it does not sufficiently differentiates between self-stigmatization and stigmatization from outside), "During my treatment I was supported in developing skills that I can also use in my life" (eliminated as the "life" was too unspecific), "I experienced support and safety during the treatment" (eliminated as it mixes two items), "During my treatment I was able to deal with my own situation" (eliminated as it was too vague), "I was given sufficient time during the treatment" (eliminated due to redundancy), "The team encouraged users to support one another" (eliminated as it does not thematize exchange between the users).

Results of the Pilot Survey

Using the alpha maximization method, nine of the remaining 16 items were found to have relatively low discriminatory power. Considerations of the research team led to the retention of four items relating to the characteristics of *Compatibility with everyday life, Safety, Time, Solidarity*, and the elimination of five items relating to the characteristics of *Autonomy* (1 item), *Continuity* (1 item), *Knowledge* (1 item), and-unfortunately- *Avoidance of coercion* (2 items). The items relating to the last characteristic were eliminated due to comments of the respondents which clearly indicated they had difficulties answering the corresponding questions. The final version of the scale contained 11 items (**Table 2**), one item each for *Flexibility, Activity, Avoidance of stigmatization, Compatibility with everyday life, Autonomy, Safety, Continuity, Intensity, Knowledge, Time, Solidarity*. The Cronbach's alpha value for the overall scale was 0.82 (0.77–0.88).

Validation of the NEPT Research Tool

A sample of 374 participants was tested during the 15 months follow-up of the PsychCare study. Because of missing data, 47 cases were excluded from further analyzes. The final sample included 327 people who were treated in 14 mental health centers, including 140 male and 187 female participants that were part of the study. The mean age was 47 (±13.48) years for the men, and 47.9 (±13.94) years for the women. **Table 1** shows the mean scores of the NEPT items for both genders. The mean total NEPT score for the entire sample was 4.02 (±1.19). Women [M (SD) = 4.06 (0.71)] had a slightly higher total score than men [M (SD) = 3.95 (0.68)].

Internal Consistency

Table 2 shows the inter-correlations between the remaining 11 items as well as correlations between the items and the NEPT total score. All correlations were significant at the level not $<p < 0.01$ except for the correlation between the Items *Compatibility with everyday life* and *Solidarity*. Except for these two items, the coefficients ranging from 0.54 to 0.77 were calculated for the corrected item-total correlations, which indicated adequate homogeneity of items. The correlations of the items *Compatibility with everyday life* and *Solidarity* were 0.45 and 0.44, respectively, which indicated that these items contributed relatively less to the tool. According to the inter-item correlation matrix, no items were above 0.80, indicating a lack of multicollinearity (41). The Cronbach's alpha coefficient for the summary scale was good (0.89). The Cronbach's alpha coefficient if item deleted ranged from 0.87 to 0.89, indicating that no items were unreliable. However, the contribution of the items *Compatibility with everyday life* and *Solidarity* for the internal consistency of the tool was critical.

Validity

Structural Validity. Prior to performing the multivariate analysis, the adequacy of the correlation matrix of the scale was checked. The observed values KMO = 0.91 and Bartlett's Sphericity Test, $\chi^2 = 1632.63$, df = 55, $p < 0.001$ supported a multivariate analysis, which was carried out using PCA. Without fixing the number of components to extract, the PCA identified two components with Eigenvalue (Kaiser's criterion) >1 (5.37 and 1.03), conjointly accounting for 58.16% of the total variance: This solution clearly produced a general unipolar component, all items with positive loadings > 0.50, ranging from 0.53 (Item: *Compatibility with everyday life*) to 0.84 (Item: *Knowledge*). The second component aggregated items with lower component loadings (no items attained the component loading cut-off) and therefore was initially regarded as dubious. However, subsequent application of other criteria (Velicer MAP criterion and Velicer MAP criterion/4th power) confirmed the 1-component solution, which accounted for 48.65% of the total variances. Based on these results, the unidimensional structure of the tool was acknowledged.

The Jonckheere-Terpstra test results (z = 1.859, $p = 0.03$) showed that the NEPT total score differed based on the experiences in order (i.e., three independent groups: "centers providing standard health care, Mdn = 3.9," "centers providing both FIT and standard treatment health care, Mdn = 4.0," and "centers exclusively providing FIT treatment, Mdn = 4.1") and therefore provided known-groups validity evidence for the scale.

Concurrent Validity. The Pearson's correlation analysis to assess the relationship between ZUF-8 total score and NEPT total score in a total of 299 participants preliminarily showed the relationship to be monotonic, as assessed by visual inspection of a scatterplot (see **Figures 1**, **3**). As expected, there was a strong positive correlation between ZUF-8 total score and NEPT total score rs = 0.56, $p < 0.001$, indicating the tools are measuring comparable constructs. Using linear regression analysis, a significant association ($p < 0.001$) between total scores

TABLE 1 | Mean scores of NEPT items and total score.

Item	Men (*N* = 140)		Women (*N* = 187)		Full sample (*N* = 327)	
	M	**SD**	**M**	**SD**	**M**	**SD**
Flexibility	3.96	1.21	4.06	1.18	4.02	1.19
Activity	3.97	0.99	3.89	1.1	3.93	1.05
Preventing (stigmatization)	4.3	0.8	4.20	1.04	4.24	0.94
Compatibility with everyday life	4.03	1.05	4.01	1.16	4.02	1.11
Autonomy	3.9	1.02	4.09	0.91	4.01	0.96
Safety	4.16	0.89	4.26	0.84	4.22	0.86
Continuity	4.02	1.01	4.22	0.87	4.14	0.93
Intensity	3.92	0.98	4.12	0.95	4.04	0.96
Knowledge	3.97	1.04	4.07	0.99	3.95	1.02
Time	3.62	1.08	3.80	1.05	3.72	1.07
Solidarity	3.81	1.04	3.96	1.03	3.9	1.04
Total score	3.95	0.68	4.06	0.71	4.02	0.70

TABLE 2 | Correlations on NEPT items and Cronbach's alpha (α).

Item	1	2	3	4	5	6	7	8	9	10	11
1 Flexibility	1										
2 Activity	0.41	1									
3 Preventing (stigmatization)	0.53	0.52	1								
4 Compatibility with everyday life	0.38	0.31	0.36	1							
5 Autonomy	0.39	0.40	0.49	0.46	1						
6 Safety	0.46	0.35	0.55	0.35	0.52	1					
7 Continuity	0.37	0.23	0.38	0.36	0.45	0.45	1				
8 Intensity	0.44	0.45	0.58	0.35	0.48	0.57	0.43	1			
9 Knowledge	0.45	0.43	0.58	0.44	0.56	0.62	0.45	0.77	1		
10 Time	0.43	0.46	0.44	0.37	0.52	0.47	0.44	0.53	0.6	1	
11 Solidarity	0.20	0.33	0.34	0.11	0.27	0.40	0.25	0.41	0.38	0.42	1
Corrected item total scale correlation	0.56	0.54	0.69	0.45	0.63	0.71	0.55	0.73	0.77	0.67	0.44
Cronbach's α if item deleted	0.88	0.88	0.87	0.89	0.88	0.87	0.88	0.87	0.87	0.87	0.89

of both scales was found. The R^2 for the overall model was 0.33 (adjusted $R^2 = 0.32$), indicative for a substantial goodness-of-fit according to Cohen (41).

DISCUSSION

This paper presents the construction and validation of a collaboratively generated, preliminary research tool to evaluate the experiences and fulfillment of needs during psychiatric treatment from the perspective of service users. The instrument showed good internal consistency and its structural validity examination suggested its unidimensional structure. On known-group validity, a linear increasing trend of the total instrument score was observed across three independent mental health hospital groups as the level of flexible and integrative (FIT) psychiatric treatment increased. In addition, there was evidence for convergent validity assessed against the ZUF-8 as the criterion measure.

"Experience" as a Construct

Our research tool operationalizes how psychiatric treatment was experienced by the users in relation to their needs. This focus fits the growing interest in assessing patients' experiences with health care services, meanwhile representing one of the three pillars in assessing the quality of health care services alongside clinical effectiveness and patient's safety (36, 37, 54). Online platforms for user input as well as internet-based reviews and ratings are increasingly developed to make room for critical feedback on the health care system and to give more space to the user experience (55). Quality assurance is increasingly focused on the user experience, with the aim of transforming care systems accordingly (56). And the users' experiences are playing an increasing role in research and evaluation, often justified on grounds of their intrinsic value, or findings that demonstrate associations between positive experiences and patient adherence, safety culture, and service utilization (37, 54).

Yet, a clear definition of what exactly counts as an experience is often lacking, most probably due to the complex nature of

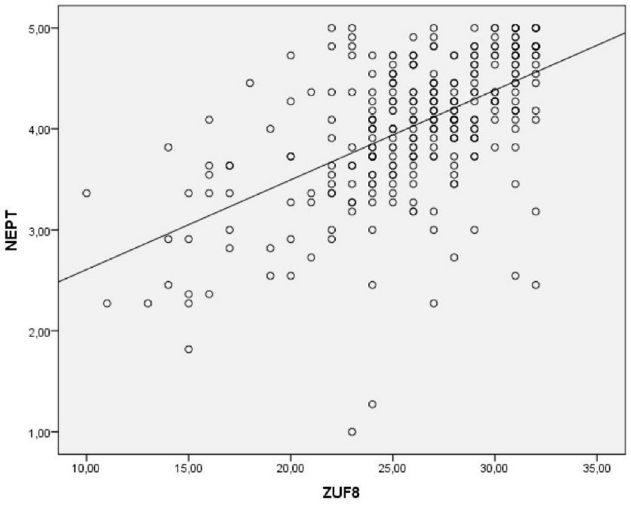


FIGURE 3 | Scatterplot presenting the linear relationship between the ZUF-8 total score and NEPT total score. ZUF-8, German version of the Client Satisfaction Questionnaire CSQ-8; NEPT, Needs and Experiences in Psychiatric Treatment scale. Solid line represents a hyppthetical 1:1 relationship between total scores of both instruments.

this construct (54). In the field of health service research, most confusingly, various notions are used interchangeably, such as user/patient-perspective, -reports, -perception, or -satisfaction Ahmed (36). In this manuscript and following Ahmed (36) and Price (54), experience refers to any users' perceptions of both objective facts and subjective evaluations ("Erleben" in German), also reflecting the evaluation of structures and processes that are not directly observable by them. In this sense, experience is an inherently multi-dimensional construct, encompassing needs, preferences, hopes, and expectations (57). It is deeply value-based at the same time opening-up potentials to serve as a useful proxy for assessing the quality of a received service.

As widely described, experience resembles the outcome parameter of patient satisfaction (37). This correspondence was confirmed by our results that demonstrated a convergent validity of both these constructs. Yet, the construct of ”experience“ was chosen, as it focusses more on concrete situations and is less reflexively charged (58). Further, as experiences are always intertwined with how they are evaluated, in our case with the question of what the treatment *was* or *should have been like* for the users, our construct also seems to relate to users' needs, as the extent to which a lack felt by the user had been eliminated through the services offered by the institution (59). Further, our construct generalizes experiences beyond those that merely relate to FIT departments, also building on users' experiences with the control group services. The FIT models having a broader scope in providing insights for the further development of the German mental health care system, our construct may be perceived to provide for a more general measure of ”good mental health care“ from the perspective of users- a hypothesis that will have to be confirmed in future studies.

Both experience- and satisfaction-based evaluation instruments are susceptible to subjective bias, being strongly linked to previous expectations, subjective judgment, social expectancy, and divergent perspectives (36, 37). In this context, more facts-based evaluation approaches are needed that increase objectivity in the evaluation of services, at the same time diminishing the possibilities for subjective interpretation. Examples in this context can be drawn from the development of fact-based PREMS and PROMS models (60, 61) that aim at evaluating key situations. A further development of our preliminary research tool in this direction, building on the qualitative findings of our participatory process evaluation (31), is planned as well as both its validation across various treatment models and care contexts.

Impact of the Collaboration

Our work has shown that participatory-collaborative research undertaken together by CR and EE is indeed possible even within the confines of a rather conventional mental health research project. This collaboration was not free from academic, structural inequalities [see Section Cooperation Within the Group and (32)], at the same time opening-up space for the researchers with experiential expertise to contribute with their specific knowledge, leading to the development of the experiential components and the instrument based on them. In our view, the framework of a process evaluation, as it is recommended in the MRC Guidelines (21), is well suited to host such a form of systematic collaboration. In contrast, the design requirements related to other parts of the PsychCare study, e.g., using fixed outcome measures or analyzing routine data or health economic parameters, would have generated significantly less opportunities for such collaborative work. Thus, the largely inductive-qualitative logic of a process evaluation (62) seems to suit research involving a collaborative approach and may enable, as in our project, the step-by-step development of a collaboratively generated instrument to be used as an evaluative research tool.

As described, our collaborative work was built upon a previous non-collaborative evaluation of German FIT models during the EvaMode64b precursor project that- despite of the fact that it aimed at evaluating user experiences too- resulted into the development of a set of components useful to assess FIT specific processes and structures (25). Thus, the ongoing collaboration between researchers with and without experiential expertise within the PsychCare study enabled us to develop a research tool that is now more in line with the needs and experiences of service users, a finding that is also described in the literature: Opinions on what is and is not considered good care may differ largely, depending on whether users or practitioners have been questioned and by whom the related evaluative criteria have been developed and/or established (17, 63–66). In this context, the Basque scientist Joan Trujols introduced the term "user generated" (versus "user-valued" and "-centered") to elucidate not only the orientation of a scale but also its ways of generation (67). Referring to our research aim- the evaluation of users' experiences- we affirm that it is essential for researchers with experiential expertise to be included in all steps of a research process and to be entitled to have substantial decision-making power.

Contrasting to this assertion, and as stated in the introduction, participatory, user or collaboratively generated scales are still scarce. Our research tool shares features with the VOICE instrument that is designed to evaluate experiences and opinions on psychiatric treatment (12). Although the items in VOICE are aimed more at evaluating the structural quality of the provision of mental health care, similar items can be found in both scales, for example the question of continuity of everyday activities or the high level of availability of support from staff. In contrast, the CEO-MHS Questionnaire designed by Oades et al. and equally based on a participatory construction process, is an instrument to measure satisfaction and therefore refers less directly to the situational and objectifiable experiences of psychiatric treatment (14). Finally, the items of the PREM construct by Wallang (68) resemble in their operationalization (I-sentences) and to some extent also domains ("I feel safe," "I feel supported," "I feel independent" etc.) but unfortunately lacks a clear description of how its development was co-produced.

In contrast, PREM mental health scales that have been developed in conventional, non-participatory ways widely diverge in their domains and operationalization from the research tool developed in our project: As much as we appreciate (69) stressing on the need of PREM scales for scientific or routine evaluation, the domains of their scale do not seem to sufficiently specify, what they mean by "quality" or "good care." As answers to these questions can only be normative, a lack of participatory engagement in their developmental process seems to be perilous. Thomas et al. (70) developed a PREM scale for evaluating the experiences of an emergency department, and, thus, depart from our project in their research aim. The DIALOG instrument incorporates both PROM and PREM items, the latter being only a few and rather broad in their scope (71). These only few examples, as well as our attempt of comparison, underscore the urgent need for collaborating with researchers with experiential expertise in the construction of PREM scales. As stated by various authors (4, 71), user-oriented services may only develop if the instruments to evaluate them will be better grounded in their perspectives and experiences into the future.

Limitations

The participants of the general study sample were recruited from very diverse mental health hospital departments and therefore may differ to those in the pilot study sample that was conducted in only one department, in which some of FIT related aspects, e.g., home treatment, were barely implemented. Further, the limited project resources did not allow for a broader participatory negotiation of the developed, experiential components beyond the expert panel and the qualitative part of our process evaluation. Maybe as a result, they focus on experiences and needs of a "higher order," rather neglecting more basic aspects of the service delivery, such as spaces for privacy, the quality of the served food, or the hygienic conditions of the treatment context. Fourth, we relied on self-report measures for assessing needs and experiences in psychiatric treatment which may have resulted in both error and bias in their measurement. As stated above, objective measurements of needs and experiences were not used and wait for further development. Our lack of a "gold standard" metric against which to compare needs and experiences limits our understanding of their concurrent validity. Finally, this study had a cross-sectional design: additional longitudinal studies in different mental health care settings are needed to establish psychometric properties of the NEPT research tool over time.

Conclusions

Our project resulted in a psychometrically robust, object-appropriate, preliminary research tool that in its orientation corresponds to the interests and knowledge of users and so-called survivors of psychiatric treatment. As such, it may be perceived as a contribution to better align mental health care with the inherently value-based experiences and judgments of their users, an endeavor that is so urgently needed (4, 72, 73). The greatest methodological strength of our work is the systematic form of collaboration between researchers with and without experiential expertise within the framework of a prospective, controlled mental health services research design. By adopting a participatory process evaluation method, this collaboration took place in each study phase, which led to the results described above. Thus, although being constrained by the confines of a mental health service research epistemology, this collaborative knowledge production was possible at the level of process evaluation and can be reproduced accordingly in other projects.

We conclude by taking a critical look at the inevitable "side effects" of such an approach. There is great debate over the extent to which the provision of specific knowledge and approaches of survivors and researchers with experiential expertise in the context of projects such as ours are appropriated or co-opted by psychiatry without actually improving the conditions of care or services (74). Since the influential text of the American activist Judi Chamberlin "On our Own" (75), the question remains as to whether the experiential knowledge of people and researchers with experiential expertise are more useful if primarily incorporated into the conceptual and practical development of alternatives to psychiatry. We, as authors, are not sure how to answer this question, but it is important for us to point out the danger of such appropriation, also to ensure a continuous and fundamental problematization of this topic in similar projects of participatory and collaborative research.

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 an Ethics Vote of the TU Dresden dated 07.09.2017 was available. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

SP and HK were responsible for the draft of this manuscript. RKG, JZ, LG, PJ, TB, and YI contributed to the research process, interactive reviewing, literature search, interpretation of literature, and helped to draft the final version of the manuscript. CS, AN, FB, BS, MH, and JS revised the article critically. All authors approved the final version to be published.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2022.781726/full#supplementary-material

REFERENCES

1. Carr S. ‘I am not your nutter’: a personal reflection on commodification and comradeship in service user and survivor research. *Disabil Soc.* (2019). 34:1140–53. doi: 10.1080/09687599.2019.1608424
2. Russo J. *Survivor-Controlled Research: A New Foundation for Thinking about Psychiatry and Mental Health* (2012).
3. Rose D, Evans J, Sweeney, A. A model for developing outcome measures from the perspectives of mental health service users. *Int rev psychiatry.* (2011) 23:41–6. doi: 10.3109/09540261.2010.545990
4. Rose D. Service user views and service user research in the journal of mental health. *J Ment Health.* (2011) 20:423–8. doi: 10.3109/09638237.2011.613959
5. Ingram, R. *Doing mad studies: making (non)sense together. Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice.* (2016) Available online at: https://journals.library.mun.ca/ojs/index.php/IJ/article/view/1680. (accessed: 12.9.2021).
6. von Unger, H. *Partizipative Forschung*. New York, NY: Springer Fachmedien Wiesbaden. (2014).
7. INVOLVE. *Briefing note two: What is public involvement in research?—INVOLVE*. (2012). Available online at: www.invo.org.uk. (accessed: 12.9.2021).
8. Slay, J. & Stephens, L. *Co-Production in Mental Health: A Literature Review*. London: New Economics Foundation/Mind (2013).
9. SURE (2001). https://www.kcl.ac.uk/research/sure, (accessed: 12.9.2021).
10. Rose D, Sweeney A, Leese M, Clement S, Jones I, Burns T, et al. Developing a user-generated measure of continuity of care: Brief report. *Acta psychiatr Scand.* (2008) 119:320–4. doi: 10.1111/j.1600-0447.2008.01296.x
11. Rogers ES, Chamberlin J, Ellison ML, Crean, T. A consumer-constructed scale to measure empowerment among users of mental health services. *Psychiatr Serv.* (1997) 48:1042–7. doi: 10.1176/ps.48.8.1042
12. Evans J., Rose D., Flach C., et al. VOICE: developing a new measure of service users’ perceptions of inpatient care, using a participatory methodology. *J Ment Health.* (2012) 21:57–71. doi: 10.3109/09638237.2011.629240
13. Neil ST, Kilbride M, Pitt L, Nothard S, Welford M, Sellwood W, et al. The questionnaire about the process of recovery (QPR): A measurement tool developed in collaboration with service users. *Psychosis.* (2009) 1:145–55. doi: 10.1080/17522430902913450
14. Viney LL, Oades LG, Strang J, Eman Y, Lambert WG, Malins G, et al. *A Framework for Consumers Evaluating Mental Health Services.* London: University of Wollongong, Illawarra Institute for Mental Health (2004).
15. Soltmann B, Neumann A, March S, Weinhold I, Häckl D, Kliemt R, et al. Multiperspective and multimethod evaluation of flexible and integrative psychiatric care models in germany: study protocol of a prospective, controlled multicenter observational study (PsychCare). *Front Psychiatry*. (2021). 12:659773. doi: 10.3389/fpsyt.2021.659773
16. Johne J, von Peter S, Schwarz J, Timm J, Heinze M, Ignatyev, et al. Evaluation of new flexible and integrative psychiatric treatment models in Germany- assessment and preliminary validation of specific program components. *BMC Psychiatry.* (2018) 18:1. doi: 10.1186/s12888-018-1861-1
17. Gillard S, Borschmann R, Turner K, Goodrich-Purnell N, Lovell K, Chambers M. ’What difference does it make?’ Finding evidence of the impact of mental health service user researchers on research into the experiences of detained psychiatric patients. *Health Expect.* (2010). 13:185–94. doi: 10.1111/j.1369-7625.2010.00596.x
18. Lambert N, Carr, S. ’Outside the Original Remit’: Co-production in UK mental health research, lessons from the field. *Int J Ment Health Nurs.* (2018). 27:1273–81. doi: 10.1111/inm.12499
19. Williams O, Sarre S, Papoulias C, Knowles S, Robert G, Beresford P, et al. Lost in the shadows: reflections on the dark side of co-production. health research policy and systems. *Health Res Policy Syst.* (2020) 18:43. doi: 10.1186/s12961-020-00558-0
20. International Collaboration for Participatory Health Research (ICPHR). *Position Paper 1: What is Participatory Health Research? Version: Mai 2013. Berlin: International Collaboration for Participatory Health Research.* (2013)
21. UKRI. https://mrc.ukri.org/research/policies-and-guidance-for-researchers/good-research-practice/ (2021). (accessed: 12.9.2021).
22. von Peter S, Ignatyev Y, Johne J, Indefrey S, Kankaya O, Rehr B, et al. Evaluation of flexible and integrative psychiatric treatment models in germany- a mixed-method patient and staff-oriented exploratory study. *Front Psychiatr.* (2019) 9:785. doi: 10.3389/fpsyt.2018.00785
23. Gemeinsamer Bundesausschuss. https://innovationsfonds.g-ba.de/projekte/versorgungsforschung/psychcare-wirksamkeit-sektorenuebergreifender-versorgungsmodelle-in-der-psychiatrie-eine-prospektive-kontrollierte-multizentrische-beobachtungsstudie.52, (2021). (accessed: 12.9.2021).
24. von Peter S, Ignatyev Y, Indefrey S, Johne J, Schwarz J, Timm J, et al. Spezifische Merkmale zur Einstufung der Modellversorgung nach § 64b SGB V. *Der Nervenarzt.* (2018) 89:559–564. doi: 10.1007/s00115-017-0459-z
25. von Peter S, Schwarz J, Bechdolf A, Birker T, Deister A, Ignatyev Y, et al. Implementation of new flexible and integrative psychiatric care models (According to §64b SGB V) in Rural Northern Germany in comparison to federal territory. *Das Gesundheitswesen.* (2019) 19:2. doi: 10.1055/a-0945-9851
26. Schwarz J, Zeipert M, Ignatyev Y, Indefrey S, Rehr B, Timm J, et al. Implementation and stakeholders’ experiences with home treatment in germany’s integrative and flexible psychiatric care models—a mixed-methods study. *Psychother, Psychosom Medizinische Psychol.* (2020) 70:65–71. doi: 10.1055/a-0942-2163

27. Ignatyev Y, Mundt A, von Peter S, Heinze, M. Hospital length of stay among older people treated with flexible and integrative psychiatric service models in Germany. *Int J of Geriatr Psychiatry*. (2019) 34:1557–64. doi: 10.1002/gps.5165
28. Baum F, Schoffer O, Neumann A, Seifert M, Kliemt R, March S, et al. (2020). Effectiveness of global treatment budgets for patients with mental disorders-claims data based meta-analysis of 13 controlled studies from Germany. *Front Psychiatry*. (2020). 11:131. doi: 10.3389/fpsyt.2020.00131
29. Neumann A, Baum F, Seifert M, Schoffer O, Kliemt R, March S, et al. Reduction of days in inpatient care in psychiatric hospitals with flexible and integrated treatment for patient-centered care with a global budget—results with three-year follow-up from the evaluation study EVA64. *Psychiatr Prax*. (2021). 48:127–34. doi: 10.1055/a-1274-3731
30. Schwarz J, Bechdolf A, Hirschmeier C, Hochwarter S, Holthoff-Detto V, Mühlensiepen F, et al. "I indeed consider it to be a temporary solution"—a qualitative analysis of the conditions and obstacles to implementation of psychiatric home-treatment in Berlin and Brandenburg. *Psychiatr Prax*. (2021). 48:193–200. doi: 10.1055/a-1274-3662
31. Glaser B, Strauß, A. *Grounded Theory: Strategien qualitativer Sozialforschung*. Göttingen: Hrsg.: Hans Huber. (2007).
32. Beeker T, Glück R, Ziegenhagen J, Göppert L, Jänchen, Patrick., et al. Designed to clash? reflecting on the practical, personal, and structural challenges of collaborative research in psychiatry. *Front Psychiatry*. (2021). 12:701312. doi: 10.3389/fpsyt.2021.701312
33. Schaefer I, Bär G. *Die Auswertung qualitativer Daten mit Peerforschenden: Ein Anwendungsbeispiel aus der partizipativen Gesundheitsforschung. Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*. (2019).
34. *NVivo Qualitative Data Analysis Software*. QSR International Pty Ltd. Version 12 (2018).
35. Jänchen P, von Peter S, Göppert L, Beeker T, Ziegenhagen J, Glück R, et al. Erlebensbezogene Merkmale für eine gute psychiatrische Versorgung aus Sicht von Nutzer*innen—Vorstellung eines ersten multivariaten Konstrukts. (forthcoming) (2021).
36. Ahmed F, Burt, J. & Roland, M. Measuring patient experience: concepts and methods. *Patient*. (2014). 7:235–41. doi: 10.1007/s40271-014-0060-5
37. Doyle C, Lennox L, Bell, D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*. (2013). 3:e001570. doi: 10.1136/bmjopen-2012-001570
38. Lawshe, C.H. A quantitative approach to content validity 1. *Personnel Psychol*. (1975). 28:563–75. doi: 10.1111/j.1744-6570.1975.tb01393.x
39. Visser AP, Breemhaar B, Kleijnen, JGVM. Social desirability and program evaluation in health care. *Impact Assessment Bulletin*. (1989). 7:99–112. doi: 10.1080/07349165.1989.9726015
40. Bühner M. *Einführung in die Test- und Fragebogenkonstruktion. Pearson Deutschland GmbH* (2011).
41. Cohen J. *Statistical Power and Analysis for the Behavioral Sciences*. Hillsdale, NJ: Lawrence (1988)
42. Fayers P, Machin, D. *Quality of Life: The Assessment, Analysis and Interpretation of Patient-Reported Outcomes*. Chichester: John Wiley & Sons (2007).
43. Tabachnick BG, Fidell, L.S. *Using multivariate statistics (5th ed.)*. Boston: Allyn & Bacon (2007).
44. Peterson RA. A meta-analysis of variance accounted for and factor loadings in exploratory factor analysis. *Market Lett*. (2000). 11:261–75. doi: 10.4236/ojs.2015.56061
45. Kim, J.-O, Mueller, C. *Factor Analysis. Statistical Methods and Practical Issues*. Newbury Park, CA: Sage Publication (1978).
46. Velicer WF, Eaton CA, Fava JL. "Construct explication through factor or component analysis: a review and evaluation of alternative procedures for determining the number of factors or components," In: editors Goffin R.D., Helmes E. *Problems and Solutions in Human Assessment*. Boston, MA: Springer (2000).
47. Presaghi F, Desimoni, M. *Random polychor.pa: A Parallel Analysis with Polychoric Correlation Matrices. r package version 1.1.4-4*. (2020).
48. Portney L, Watkins, M. *Foundations of Clinical Research: Applications to Practice*. Stamford (CT): McGraw Hill/ Appleton & Lange. (1993).
49. Conover WJ. *Practical Non-parametric Statistics*. New York, NY: Auflage, John Wiley & Sons (1999).
50. Schmidt J, Wittmann W. "Fragebogen zur Messung der Patientenzufriedenheit," In: *Diagnostische Verfahren in der Psychotherapie*. Göttingen: Hogrefe (2002).
51. Attkisson CC, Zwick, R. The client satisfaction questionnaire. psychometric properties and correlations with service utilization and psychotherapy outcome. *Eval Program Plann*. (1982). 5:233–7. doi: 10.1016/0149-7189(82)90074-X
52. Cohen J. *Statistical Power and Analysis for the Behavioral Sciences*. Hillsdale, NJ: Lawrence (1988).
53. Rose DS. Kalathil J. Power, privilege and knowledge: the untenable promise of co-production in mental "health." *Front Sociol*. (2019). 4:57. doi: 10.3389/fsoc.2019.00057
54. Anhang Price R, Elliott MN, Zaslavsky AM, Hays RD, Lehrman WG, Rybowski L, et al. Examining the role of patient experience surveys in measuring health care quality. *Med Care Res Rev*. (2014). 1:522–54. doi: 10.1177/1077558714541480
55. Gao GG, McCullough JS, Agarwal R, Jha AK. A changing landscape of physician quality reporting: analysis of patients' online ratings of their physicians over a 5-year period. *J Med Int Res*. (2012). 14:e38. doi: 10.2196/jmir.2003
56. Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, et al. Systematic review of involving patients in the planning and development of health care. *BMJ*. (2002). 325:1263. doi: 10.1136/bmj.325.7375.1263
57. Fulford K.W. Values-based practice: a new partner to evidence-based practice and a first for psychiatry? *Mens Sana Monog*. (2008). 6:10–21. doi: 10.4103/0973-1229.40565
58. Dilthey, W. "Die Geistige Welt. Einleitungen in die Philosophie des Lebens Erste Hälfte: Abhandlung zur Grundlegung der Geisteswissenschaften," *In: Gesammelte Schriften, Band V*. (1990), p. 4.
59. Arzberger K, Hondrich KO, Murck M, Schumacher, J. Was machen die Bedürfnisforscher? Klarstellungen zu einer Kritik. *Leviathan*. (1978). 6:354–73.
60. Cleary P.D. The increasing importance of patient surveys. now that sound methods exist, patient surveys can facilitate improvement. *BMJ*. (1999). 319:720–1. doi: 10.1136/bmj.319.7212.720
61. Gerteis M, Edgman-Levitan S, Walker JD, Stoke DM, Cleary PD, Delbanco, et al. L. What patients really want. *Health Manage Q*. (1993). 15:2–6.
62. Moore GF, Audrey S, Barker M, et al. Process evaluation of complex interventions: medical research council guidance. *BMJ*. (2015). 350:h1258. doi: 10.1136/bmj.h1258
63. Rose D, Thornicroft G, Slade, M. Who decides what evidence is? developing a multiple perspectives paradigm in mental health. *Acta Psychiatr Scand Suppl*. (2006). 429:109–14. doi: 10.1111/j.1600-0447.2005.00727.x
64. Russo J, Beresford, P. Between exclusion and colonisation: Seeking a place for mad people's knowledge in academia. *Disabil Soc*. (2014). 24:25. doi: 10.1080/09687599.2014.957925
65. Oades L, Law J, Marshall, S. Development of a consumer constructed scale to evaluate mental health service provision. *J Eval Clin Pract*. (2011). 17:1102. doi: 10.1111/j.1365-2753.2010.01474.x
66. Crawford MJ, Robotham D, Thana L, et al. Selecting outcome measures in mental health: the views of service users. *J Ment Health*. (2011). 20:336–46. doi: 10.3109/09638237.2011.577114
67. Trujols J, Portella MJ, Iraurgi I, Campins MJ, Siñol N, de Los Cobos JP. (2013). Patient-reported outcome measures: are they patient-generated, patient-centred or patient-valued? *J Ment Health*. (2013). 22:555–62. doi: 10.3109/09638237.2012.734653
68. Wallang P, Kamath S, Parshall A, Saridar T, Shah, M. Implementation of outcomes-driven and value-based mental health care in the UK. *Br J Hosp Med (Lond)*. (2018). 79:322–327. doi: 10.12968/hmed.2018.79.6.322
69. Fernandes S, Fond G, Zendjidjian X, Michel P, Lancon C, Berna F, et al. A conceptual framework to develop a patient-reported experience measure of the quality of mental health care: A qualitative study of the PREMIUM project in France. *J Mark Access Health Policy*. (2021) 9:1885789. doi: 10.1080/20016689.2021.1885789
70. Thomas KC, Owino H, Ansari S, Adams L, Cyr JM, Gaynes BN, et al. Patient-centered values and experiences with emergency department

and mental health crisis care. *Adm Policy Ment Health.* (2018) 45:611–22. doi: 10.1007/s10488-018-0849-y

71. Mosler F, Priebe S, Bird V. Routine measurement of satisfaction with life and treatment aspects in mental health patients—the DIALOG scale in East London. *BMC Health Serv Res.* (2020) 20:1020. doi: 10.1186/s12913-020-05840-z
72. Fisher CE, Spaeth-Rublee B, Pincus HA, for the IIMHL Clinical Leaders Group. (2013). Developing mental health-care quality indicators: toward a common framework. *Int J Qual Health Care.* (2013) 25:75–80. doi: 10.1093/intqhc/mzs074
73. Baggaley, M. Value-based healthcare in mental health services. *BJPsych Adv.* (2020) 26:198–204. doi: 10.1192/bja.2019.82
74. Penney D, Prescott, L. "The co-optation of survivor knowledge: The danger of substituted values and voice," *In: Searching for a rose garden: Challenging psychiatry, fostering mad studies. Ross-on-Wye,* England: PCCS Books. (2016), p. 35–45.
75. Chamberlin, J. *On our own: Patient-controlled Alternatives to the Mental Health System*. New York, NY: McGraw-Hill (1978).

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Character Strengths Across Disabilities: An International Exploratory Study and Implications for Positive Psychiatry and Psychology

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The purpose of this study was to examine the differences in character strengths for people with disabilities by using an international dataset by the VIA Institiute on Character. Specifically, we aimed to explore (a) the top and bottom five character strengths reported by different disability groups and all people with disabilities more broadly, and (b) group differences in each character strength and total character strengths. The investigator contacted the VIA Institute on Character (http://www.viacharacter.org/) for obtaining the dataset for the current study. After data cleaning, our sample size resulted in 11,699 people with disabilities. Among most people with disabilities, the top five character strengths scores were love of learning, honesty, appreciation of beauty and excellence, kindness, and fairness. The bottom five character strengths scores were self-regulation, perseverance, zest, spirituality, and prudence. Knowing that there is heterogeneity in character strengths across groups gives us a better understanding of the areas that people with different disabilities and conditions might thrive and provides clinicians and practitioners with a more nuanced understanding for how to possibly intervene with their clients. Positive psychiatry and psychology implications are discussed.

Keywords: disability, emotional disabilities, positive psychiatry, positive psychology, chronic condition

INTRODUCTION

According to the World Health Organization (1), over one billion people worldwide are living with some form of disabilities and chronic conditions, which translates to ∼15% of the world's population. The number of people with disabilities is increasing due to simultaneous increases in chronic health conditions and aging populations (1). People with disabilities can face different psychosocial challenges, such as functional limitations, secondary health conditions, social stigma, limited vocational functioning, and compromised community participation (2–8). Therefore, it is important to examine how to better support people with disabilities and chronic conditions and facilitate optimal psychosocial functioning through the lens of contemporary approaches such as positive psychiatry and psychology.

Shifting away from the traditional disease and pathology paradigm, positive psychology emphasizes building positive qualities rather than exclusively focusing on repairing weaknesses, aiming to understand what makes life worth living and enabling human thriving (9). Psychiatry has been defined as a subfield under medicine focusing on the diagnosis and treatment of mental illnesses (10). Recently, authors defined positive psychiatry as "the science and practice of psychiatry that seeks to understand and promote wellbeing through assessment and interventions aimed at enhancing behavioral and mental wellness" [(10), p. 2]. In recent decades, understanding disability and chronic conditions including mental illnesses has focused on holistic human functioning and the identification of human strengths and potentials (11).

Dr. Beatrice Wright, a pioneer in the rehabilitation field, promoted that psychosocial adjustment to disability and chronic conditions can be considered from a positive framework and postulated a coping vs. succumbing framework (12, 13). In this framework, *coping* focuses on an individual's positive qualities and abilities, whereas *succumbing* focuses on an individual's impairments and deficits (14). Consistent with the foundations of positive psychology, the rehabilitation field focuses on individuals with disabilities' capabilities and strengths (13, 15). Many studies have examined the effects of positive psychological characteristics (e.g., hope, resilience) on functioning and quality of life from a strength-based paradigm within the disability and rehabilitation field (5, 16–20). In the current study, we sought to illustrate variation in a particular classification of positive psychological characteristics—character strengths—in a large exploratory study of over 11,000 people with disabilities.

Character strengths are one of the foundations in the science of positive psychology (21, 22). Character strengths are defined as positive personality traits that reflect core identity, produce positive outcomes for oneself and others, and contribute to the collective good (21). Peterson and Seligman (23) developed *VIA Classification of Character Strengths* and classified 24 character strengths into six virtues: wisdom (i.e., creativity, curiosity, judgment, love of learning, perspective), courage (i.e., bravery, honesty, perseverance, zest), humanity (i.e., kindness, love, social intelligence), justice (i.e., fairness, leadership, teamwork), temperance (i.e., forgiveness, humility, prudence, self-regulation), and transcendence (i.e., appreciate of beauty and excellence, gratitude, hope, humor, spirituality). Character strengths are the psychological processes and mechanisms that depict virtues while virtues are described as the core moral characteristics that are universally valued (23). There is a large literature on the measurement, antecedents, and consequences of all 24 character strengths that suggest they play a critical role in positive psychological functioning and wellbeing [e.g., (23)]. Besides, Dahlsgaard et al. [(24), p. 2010] aimed to "create a consensual classification of human strengths while avoiding the criticism that any specific list we proposed would be culturally or historically idiosyncratic (23)." They reported that there is a convergence across place, time, and intellectual trandition about certain core virtues.

Growing research has examined the role of character strengths and character strength assessments in various disability groups, including individuals with intellectual and developmental disabilities (25, 26), multiple sclerosis [MS; (27)], traumatic brain injury [TBI; (28)], veterans with and without disabilities (29), and chronic conditions and disabilities (8). For instance, Niemiec et al. (25) discussed how building on character strengths can enhance support systems and quality of life of people with intellectual and developmental disabilities. Shogren et al. (26) examined the endorsement and psychometric properties of the *VIA Inventory of Strengths of Youth (VIA-Youth)* by exploring differences between youth with and without intellectual disability. Smedema (27) found that many character strengths played roles in the quality of life directly and indirectly through the negative effects of MS. Hanks et al. (28) found that character strengths and virtues were moderately associated with subjective wellbeing in people with mild to severe TBI. Umucu et al. (8) found that character strengths moderated the association between COVID-19 stress and the wellbeing among individuals with chronic conditions and disabilities.

More specifically, researchers have also been interested in examining the character strengths that were most frequently reported by people with disabilities. In a sample of adults with autism spectrum disorder, the most frequently reported character strengths were open-mindedness, creativity, and love of learning (30). Having a broader understanding of the character strengths reported by people with disabilities, including their commonalities and differences, provides us a broader insight into their psychological experiences, the sources of their wellbeing and quality of life, and provide a roadmap for moving forward in intervention work.

With the WHO's (1) emphasis on promoting rehabilitation services (e.g., psychiatric rehabilitation) and the increasing research attention on how character strengths make an impact on the lives of people with disabilities and chronic conditions, the purpose of this exploratory study was to examine the differences in character strengths for people with disabilities by using an international dataset by the VIA Institute on Character. Specifically, we aimed to explore (a) the top and bottom five character strengths reported by different disability groups and all people with disabilities and chronic conditions more broadly, and (b) group differences in each character strength and total character strengths. To our knowledge, this is the first study using a large international sample to explore the differences in character strengths among people with different types of disabilities and chronic conditions including emotional conditions. Given positive psychiatry and psychology focuses on positive attributes and strengths, the results of the study will contribute to the existing international positive psychology, disability, and positive psychiatry literature on the role of character strengths in people with disabilities.

METHODS

Procedure and Participants

This study was evaluated and approved by the Institutional Review Board of [blinded for review]. Upon approval of the study, the investigator contacted the VIA Institute on Character (http://www.viacharacter.org/) for obtaining the dataset for the current study. After data cleaning, our sample size resulted in 11,699 people with disabilities from across the globe.

Measures

Sociodemographic Characteristics

Sociodemographic characteristics were measured via a demographic survey. Participants responded to questions regarding their age, gender, education, employment status, disability category, urban/rural living status, and countries. Regarding countries, although most participants reported their countries; some did not. More than half of the participants were from the US (>53.9%). There were participants from Canada (>6.7%), Australia (>6.0%), and United Kingdom (>4.9%), and Brazil (>3%). There were also participants from numerous other countries such as France, Estonia, Germany, Denmark, Belgium, Argentine, Turkey, India, Japan, Mexico, Netherlands, South Africa, and New Zealand.

Character Strengths

VIA Classification of Strengths and Virtues (character strengths) were measured using the VIA Inventory of Strengths—Positive [VIA-IS-P; (31)], which is a version of the original VIA-IS (23) but exclusively uses positively worded items. The VIA-IS-P consists of a total of 96 items, measuring 24 character strengths (4 items per character strengths). Each item is rated on a 5-point Likert-type scale ranging from 1(*Very Much Unlike Me*) to 5 (*Very Much Like Me*), with higher scores indicating higher character strengths. McGrath and Wallace (32) suggested researchers use the VIA-IS-P when there are concerns regarding participants' cognitive capacity to process negatively worded items. The mean alpha coefficient of the VIA-IS-P across strengths was 0.78 (32). The mean omega (ω) value of the VIA-IS-P was 0.78 (32). For our analyses, we examined disability group differences in each of the 24 character strengths and a composite measure in which all the character strengths were averaged together to yield one total score.

Disability Status

Disability status was asked with the following question: "Are you challenged by any of the following?" Participants had the option to select any disability status among multiple options (e.g., traumatic brain injury). We categorized disability types into eight categories, which included intellectual disabilities, sensory disabilities, emotional disturbance, orthopedic impairments, other health impairments, specific learning disabilities, traumatic brain injury, and multiple disabilities.

Data Analysis

We conducted descriptive statistics to identify means and standard deviations for study variables. We used Shapiro–Wilk to check for data normality for each character strengths and total character strength scores. None of the scores fulfilled the criteria for normal distribution.

Next, we conducted Levene's test to examine homogeneity of variance on each dependent variable to test the assumption that individuals in each disability group varied in roughly homogeneous or similar ways. All of the Levene's tests were significant, showing that the groups did not have equal variances. As parametric assumptions were not met, we conducted a Kruskal–Wallis, non-parametric alternative to one-way ANOVA, to assess mean differences in character strengths and total character strengths among eight disability groups.

Finally, we used Dunn Bonferroni *post-hoc* tests to determine specific significant differences among groups. All analyses were conducted via SPSS 26.0 and DescTools (33), GmAMisc (34), and ggpubr (35) using the R Software (36).

RESULTS

Descriptive Statistics

The majority of participants (∼71%) were in the age range of 25–54. Most participants were women (72.3%), followed by men (25.7%) and others (2.0%). Regarding participants' education, about 72% of participants had at least a bachelor's degree. About 81% of participants were employed. Only 14.7% of participants reported they live in rural area. Regarding disability group, most participants had multiple disabilities (26.7%), followed by other health impairments (26.4%), emotional disturbance (23.1%), sensory disabilities (11.5%), specific learning disability (4.8%), orthopedic impairment (3.6%), intellectual disability (2.6%), and traumatic brain injury (1.2%). **Table 1** demonstrates means and SDs for variables across disability groups.

Character Strengths Profiles

We created character strengths profiles for each disability based on participants' mean scores for each CS scores. **Figures 1**, **2** demonstrate character strengths profiles for each disability group and overall character strengths profile. **Figure 3** represents radar chart for disability groups by character strengths.

Intellectual Disability Group (IDG; 2.6%)

Among people with intellectual disabilities, the top five character strengths scores were love of learning, honesty, fairness, judgment, and appreciation of beauty and excellence. The bottom five character strengths scores were self-regulation, perseverance, zest, spirituality, and leadership.

Sensory Disability Group (SDG; 11.5%)

Among individuals with sensory disabilities, the top five character strengths scores were honesty, love of learning, fairness, appreciation of beauty and excellence, and kindness. The bottom five character strengths scores were self-regulation, perseverance, zest, spirituality, and bravery.

Emotional Disturbances Group (EDG; 23.1%)

Among people with emotional disturbances, the top five character strengths scores were appreciation of beauty and excellence, love of learning, kindness, honesty, and fairness. The bottom five character strengths scores were self-regulation, zest, perseverance, spirituality, and hope.

TABLE 1 | Demographic information and character strengths group characteristics and differences.

Characteristics	**Intellectual disabilities (IDG) $n = 306$**	**Sensory disabilities (SDG) $n = 1,341$**	**Emotional disturbances (EDG) $n = 2,705$**	**Orthopedic impairments (OIG) $n = 426$**	**Other health impairment $n = 3,090$**	**Specific learning disabilities (SLDG) $n = 565$**	**Traumatic brain injury (TBIG) $n = 139$**	**Multiple disabilities (MDG) n = 3,127**	**Test**
Women, *n* (%)	177 (57.8)	888 (66.2)	2,066 (76.4)	301 (70.7)	2,282 (73.9)	399 (70.6)	101 (72.7)	2,249 (71.9)	$p < 0.05^a$
Virtues and Character Strengths									Group Differences Test[b]
Wisdom, mean (SD)	19.57 (2.35)	19.31 (2.31)	18.89 (2.49)	19.43 (2.46)	19.38 (2.39)	19.49 (2.29)	19.89 (2.45)	19.40 (2.51)	$H^a = 96.46$*
Creativity, mean (SD)	3.72 (0.87)	3.55 (0.79)	3.54 (0.82)	3.64 (0.77)	3.63 (0.82)	3.73 (0.81)	3.79 (0.79)	3.71 (0.80)	$H^a = 93.60$*
Curiosity, mean (SD)	3.93 (0.72)	3.90 (0.67)	3.77 (0.74)	3.91 (0.72)	3.89 (0.71)	4.00 (0.67)	4.01 (0.69)	3.89 (0.73)	$H^a = 82.74$*
Judgment, mean (SD)	3.96 (0.62)	3.88 (0.58)	3.77 (0.64)	3.88 (0.63)	3.88 (0.59)	3.80 (0.59)	3.90 (0.58)	3.84 (0.63)	$H^a = 61.70$*
Love of learning, mean (SD)	4.13 (0.66)	4.07 (0.65)	3.98 (0.72)	4.06 (0.67)	4.07 (0.68)	4.05 (0.65)	4.22 (0.65)	4.07 (0.69)	$H^a = 49.38$*
Perspective, mean (SD)	3.81 (0.71)	3.88 (0.65)	3.81 (0.70)	3.93 (0.65)	3.89 (0.66)	3.88 (0.66)	3.95 (0.71)	3.87 (0.71)	$H^a = 28.88$*
Courage, mean (SD)	13.30 (2.28)	13.78 (2.13)	12.80 (2.15)	2.17 (2.25)	13.37 (2.25)	13.53 (2.02)	14.44 (1.99)	13.17 (2.38)	$H^a = 282.81$*
Bravery, mean (SD)	3.42 (0.84)	3.39 (0.77)	3.37 (0.81)	3.50 (0.75)	3.46 (0.81)	3.56 (0.75)	3.69 (0.80)	3.51 (0.83)	$H^a = 90.55$*
Honesty, mean (SD)	3.98 (0.63)	4.09 (0.59)	3.93 (0.66)	4.09 (0.61)	4.03 (0.64)	3.96 (0.62)	4.25 (0.57)	4.00 (0.67)	$H^a = 91.94$*
Perseverance, mean (SD)	2.89 (0.89)	3.09 (0.86)	2.76 (0.87)	3.10 (0.82)	2.85 (0.89)	2.73 (0.77)	3.20 (0.77)	2.77 (0.94)	$H^a = 211.03$*
Zest, mean (SD)	3.00 (0.96)	3.21 (0.83)	2.73 (0.87)	3.18 (0.88)	3.01 (0.90)	3.28 (0.83)	3.29 (0.84)	2.87 (0.96)	$H^a = 408.61$*
Humanity, mean (SD)	10.69 (2.18)	11.37 (1.71)	11.37 (1.76)	11.60 (1.73)	11.59 (1.73)	11.66 (1.65)	11.75 (1.72)	11.55 (1.82)	$H^a = 87.21$*
Kindness, mean (SD)	3.91 (0.68)	3.98 (0.63)	3.97 (0.65)	4.03 (0.63)	4.02 (0.63)	4.06 (0.57)	4.03 (0.69)	4.08 (0.63)	$H^a = 54.96$*
Love, mean (SD)	3.35 (1.12)	3.65 (0.92)	3.58 (0.96)	3.68 (0.92)	3.71 (0.93)	3.71 (0.92)	3.82 (0.84)	3.65 (0.97)	$H^a = 55.27$*
Social intelligence, mean (SD)	3.43 (0.90)	3.73 (0.68)	3.81 (0.69)	3.88 (0.63)	3.85 (0.67)	3.89 (0.68)	3.89 (0.68)	3.81 (0.71)	$H^a = 98.37$*
Justice, mean (SD)	10.53 (1.86)	11.08 (1.57)	10.66 (1.67)	11.17 (1.56)	11.02 (1.63)	11.19 (1.49)	11.46 (1.76)	10.85 (1.75)	$H^a = 144.57$*
Fairness, mean (SD)	3.98 (0.69)	4.00 (0.66)	3.89 (0.74)	4.00 (0.63)	4.00 (0.69)	4.02 (0.67)	4.12 (0.67)	3.98 (0.71)	$H^a = 45.77$*
Leadership, mean (SD)	3.15 (1.03)	3.46 (0.87)	3.31 (0.92)	3.61 (0.88)	3.47 (0.89)	3.56 (0.82)	3.65 (0.96)	3.38 (0.93)	$H^a = 118.40$*
Teamwork, mean (SD)	3.39 (0.81)	3.61 (0.69)	3.46 (0.73)	3.54 (0.65)	3.54 (0.72)	3.60 (0.67)	3.69 (0.66)	3.48 (0.76)	$H^a = 72.83$*
Temperance, mean (SD)	13.36 (2.15)	13.81 (2.02)	13.07 (2.15)	13.75 (2.05)	13.43 (2.14)	13.05 (2.05)	13.86 (2.05)	13.19 (2.28)	$H^a = 156.20$*
Forgiveness, mean (SD)	3.58 (0.79)	3.67 (0.73)	3.54 (0.77)	3.72 (0.68)	3.68 (0.75)	3.71 (0.70)	3.65 (0.69)	3.63 (0.78)	$H^a = 64.65$*
Humility, mean (SD)	3.47 (0.72)	3.59 (0.67)	3.51 (0.73)	3.49 (0.65)	3.54 (0.71)	3.44 (0.71)	3.60 (0.67)	3.51 (0.72)	$H^a = 26.44$*
Prudence, mean (SD)	3.43 (0.85)	3.55 (0.79)	3.37 (0.88)	3.51 (0.83)	3.43 (0.83)	3.24 (0.82)	3.52 (0.81)	3.36 (0.88)	$H^a = 85.74$*
Self-regulation, mean (SD)	2.87 (0.87)	2.99 (0.84)	2.63 (0.89)	3.02 (0.84)	2.76 (0.90)	2.64 (0.84)	3.08 (0.87)	2.68 (0.93)	$H^a = 232.17$*
Transcendence, mean (SD)	17.62 (3.06)	18.42 (2.72)	17.18 (2.90)	18.68 (2.92)	18.14 (2.97)	18.16 (2.71)	17.91 (3.10)	17.91 (3.10)	$H^a = 273.37$*
Appreciation of beauty and excellence, mean (SD)	3.93 (0.84)	3.99 (0.70)	4.01 (0.73)	4.06 (0.70)	4.02 (0.73)	4.00 (0.72)	4.14 (0.69)	4.05 (0.74)	$H^a = 21.20$*
Gratitude, mean (SD)	3.34 (0.86)	3.64 (0.78)	3.26 (0.83)	3.64 (0.83)	3.53 (0.84)	3.53 (0.78)	3.80 (0.78)	3.42 (0.88)	$H^a = 284.89$*
Hope, mean (SD)	3.49 (0.83)	3.68 (0.72)	3.19 (0.84)	3.71 (0.75)	3.54 (0.81)	3.60 (0.74)	3.78 (0.70)	3.44 (0.87)	$H^a = 501.52$*
Humor, mean (SD)	3.71 (0.90)	3.73 (0.86)	3.57 (0.92)	3.84 (0.92)	3.74 (0.86)	3.78 (0.85)	3.75 (0.87)	3.72 (0.89)	$H^a = 82.37$*
Spirituality, mean (SD)	3.13 (1.11)	3.35 (1.01)	3.14 (1.01)	3.41 (1.02)	3.28 (1.04)	3.23 (1.01)	3.55 (0.97)	3.33 (1.03)	$H^a = 87.84$*
Character strengths, mean (SD)	85.10 (9.84)	87.80 (9.24)	84.00 (9.40)	88.55 (9.86)	86.95 (9.80)	87.11 (8.69)	90.48 (9.22)	86.08 (10.57)	$H^a = 255.79$*

[a] *Chi-square test.*

[b] *Kruskal–Wallis H test. *p < 0.05.*

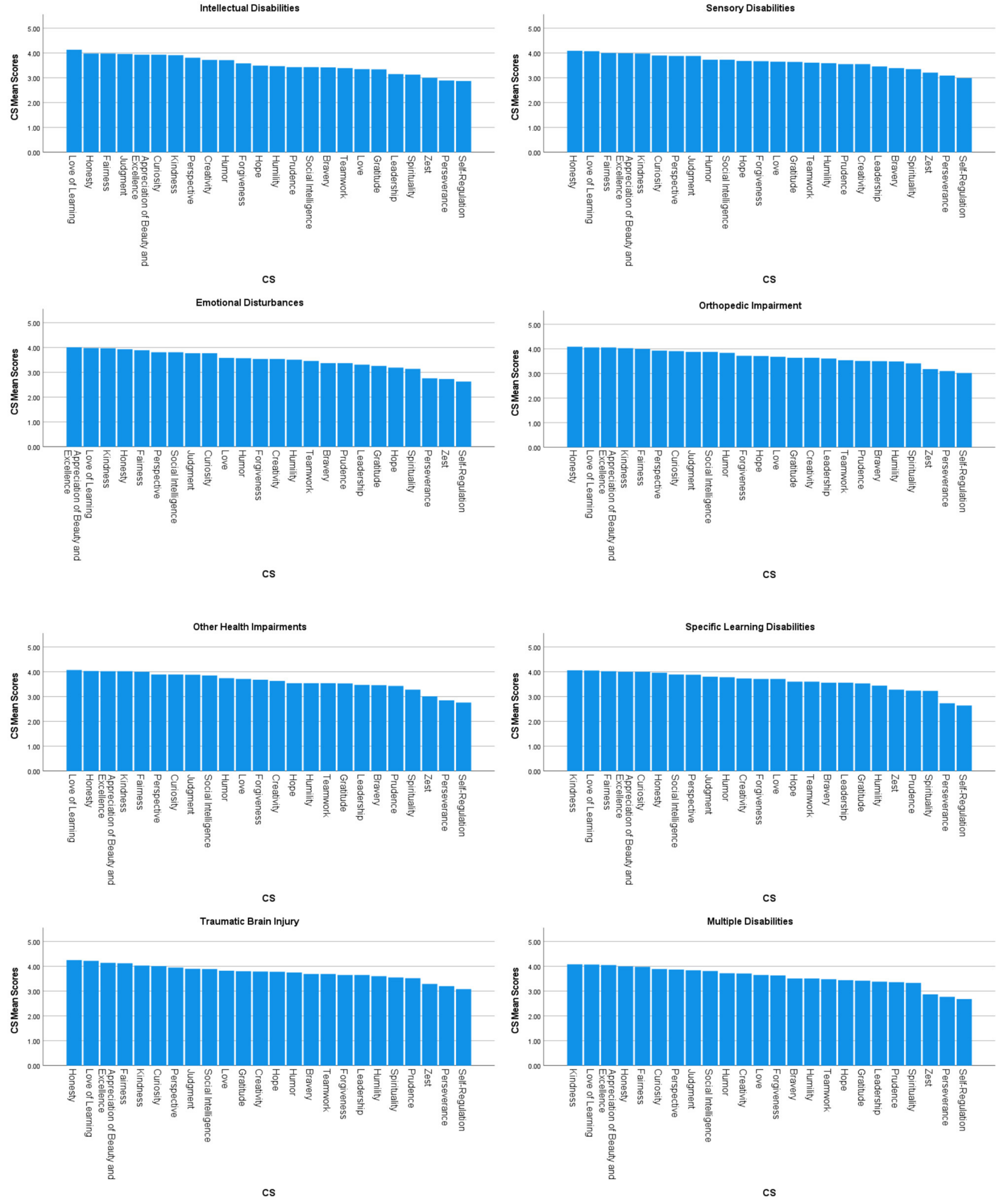

FIGURE 1 | Character strengths profiles for each disability group.

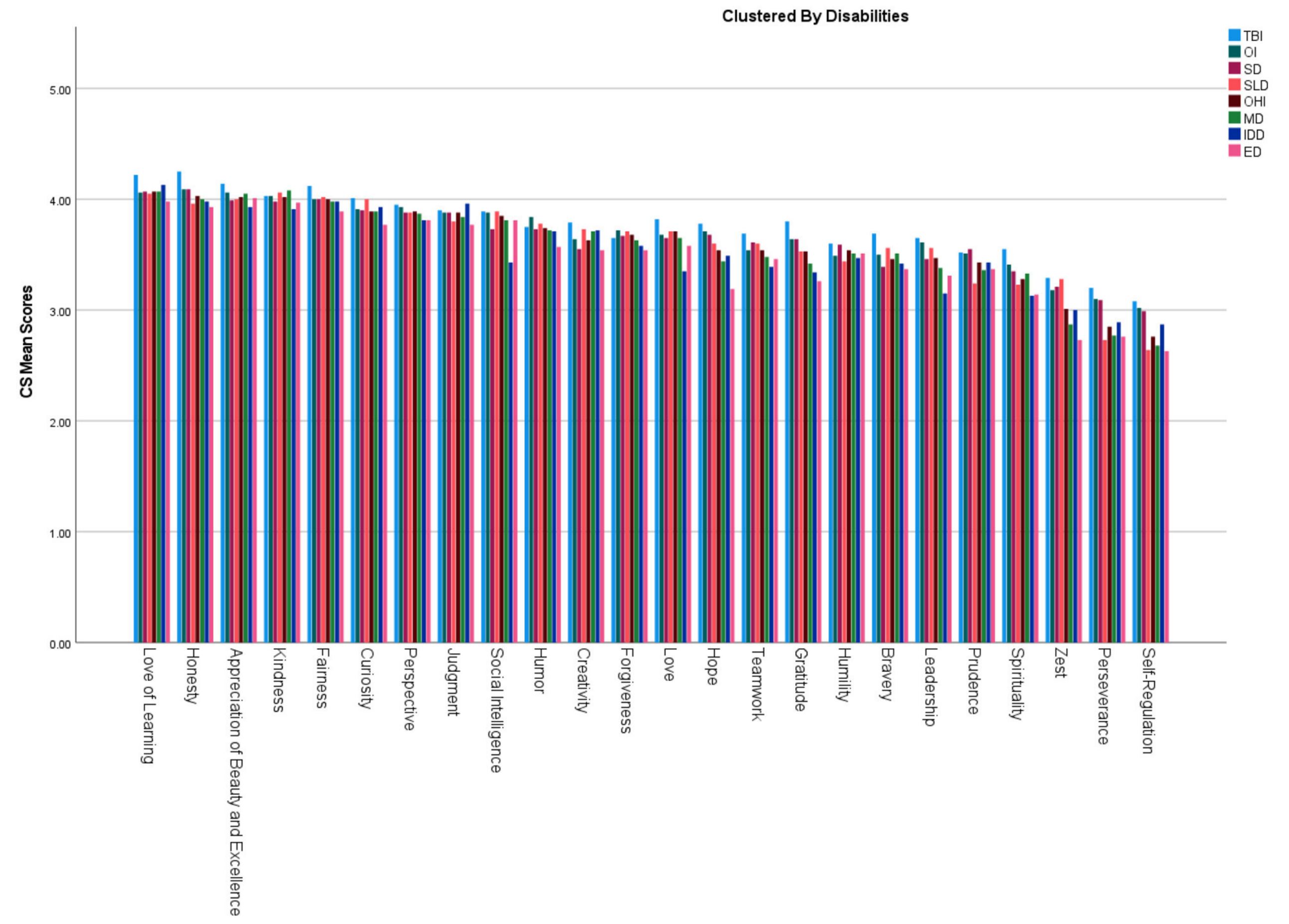

FIGURE 2 | Overall character strengths profile. TBI, Traumatic brain injury; OI, Orthopedic impairment; SD, Sensory disabilities; SLD, Speech-language disabilities; OHI, Other health impairments; MD, multiple disabilities; IDD, Intellectual disabilities; ED, Emotional disturbance.

Orthopedic Impairment Group (OIG; 3.6%)

Among people with orthopedic disabilities, the top five character strengths scores were honesty, love of learning, appreciation of beauty and excellence, kindness, and fairness. The bottom five character strengths scores were self-regulation, perseverance, zest, spirituality, and humility.

Other Health Impairments Group (OHIG; 26.4%)

Among people with other health impairments, the top five character strengths scores were love of learning, honesty, appreciation of beauty and excellence, kindness, and fairness. The bottom five character strengths scores were self-regulation, perseverance, zest, spirituality, and prudence.

Specific Learning Disabilities Group (SLDG; 4.8%)

Among people with specific learning disabilities, the top five character strengths scores were love of learning, honesty, fairness, judgment, and appreciation of beauty and excellence. The bottom five character strengths scores were self-regulation, perseverance, zest, spirituality, and leadership.

Traumatic Brain Injury Group (TBIG; 1.2%)

Among people with TBI, the top five character strengths scores were honesty, love of learning, appreciation of beauty and excellence, fairness, and kindness. The bottom five character strengths scores were self-regulation, perseverance, zest, prudence, and spirituality.

Multiple Disability Group (MDG; 26.7%)

Among people with multiple disabilities, the top five character strengths scores were kindness, love of learning, appreciation of beauty and excellence, honesty, and fairness. The bottom five character strengths scores were self-regulation, perseverance, zest, spirituality, and prudence.

Summary

Among all people with disabilities, the top five character strengths scores were love of learning, honesty, appreciation of beauty and excellence, kindness, and fairness. The bottom five character strengths scores were self-regulation, perseverance, zest, spirituality, and prudence.

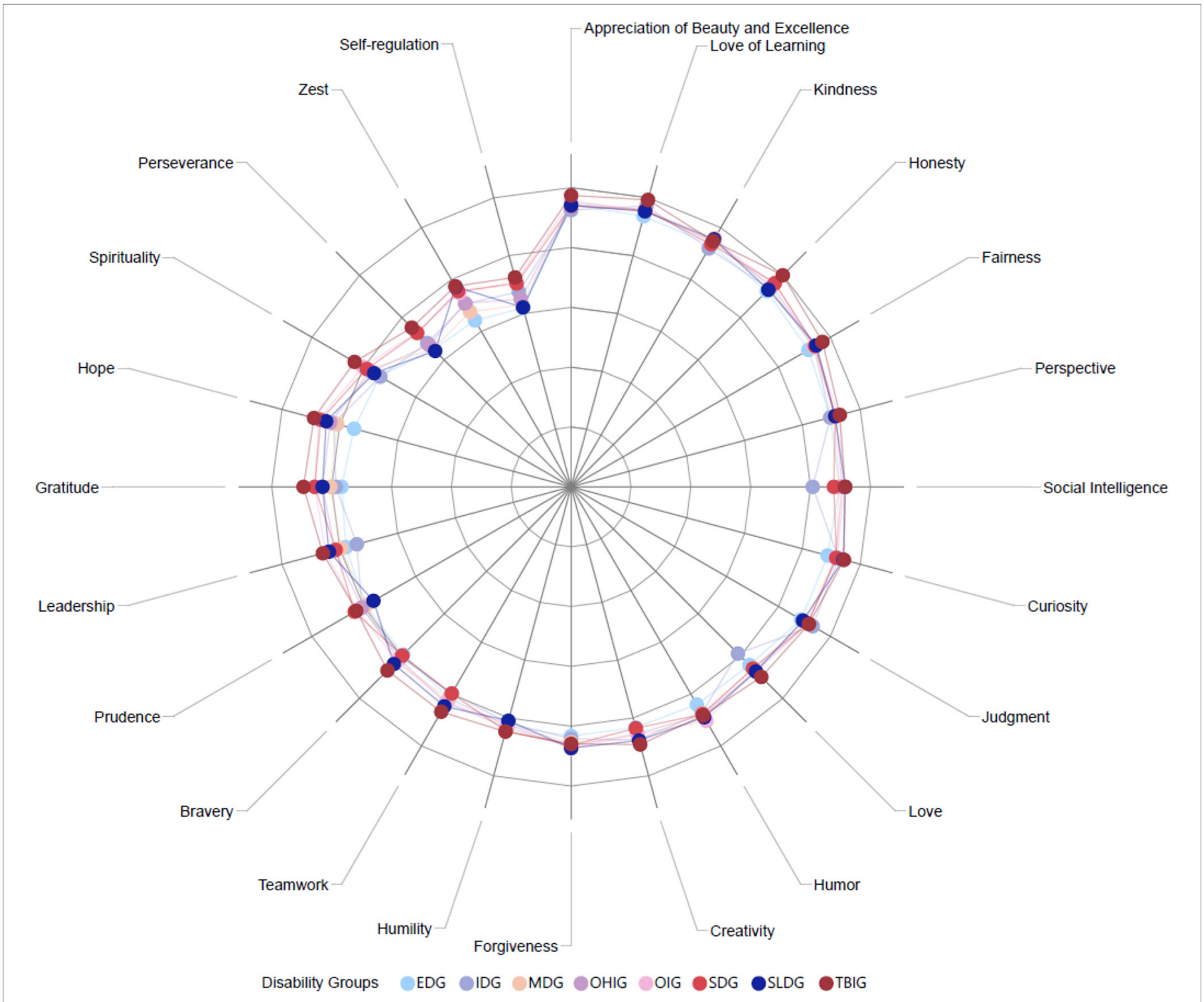

FIGURE 3 | Radar chart for disability groups by character strengths. TBI, Traumatic brain injury; OI, Orthopedic impairment; SD, Sensory disabilities; SLD, Speech-language disabilities; OHI, Other health impairments; MD, multiple disabilities; IDD, Intellectual disabilities; ED, Emotional disturbance.

Group Differences in Character Strengths Score

Kruskal–Wallis test results revealed that there were statistically significant differences in total character strengths score among the eight disability groups, $\chi^2(7) = 255.78$, $p < 0.05$. Please see **Appendix** for group differences in each character strength score.

Dunn Bonferroni *post-hoc* Analyses

Follow-up Dunn's *pos-hoc* tests were conducted to examine pairwise differences among the disability groups. Significance values have been adjusted by the Bonferroni correction for multiple tests. Regarding total character strengths (CS) total scores, SDG [mean rank difference (MRD) = 924.44, $p < 0.05$], OIG (MRD = 1255.23, $p < 0.05$), OHIG (MRD = 662.52, $p < 0.05$), and TBIG (MRD = 1864.94, $p < 0.05$) had significantly higher CS total scores compared with IDG. SDG (MRD = 1298.14, $p < 0.05$), OIG (MRD = 1628.94, $p < 0.05$), OHIG (MRD = 1036.23, $p < 0.05$), SLDG (MRD = 1073.41, $p < 0.05$), TBIG (MRD = 2238.65, $p < 0.05$), and MDG (MRD = 722.90, $p < 0.05$) had significantly higher CS total scores compared with EDG. OHIG (MRD = −592.71, $p < 0.05$) had significantly lower CS total score compared with OIG. TBIG had significantly higher CS total scores compared with OHIG (MRD = 1202.41, $p < 0.05$), SDG (MRD = 940.50, $p < 0.05$), and SLDG (MRD = 1165.23, $p < 0.05$). MDG had significantly lower CS total scores than SDG (MRD = −575.24, $p < 0.05$), OIG (MRD = −906.03, $p < 0.05$), OHIG (MRD = −313.32, $p < 0.05$), and TBIG (MRD = −1515.74, $p < 0.05$). Please see **Appendix** and **Table 1** for Dunn Bonferroni *post-hoc* Analyses results for each CS.

DISCUSSION

This study is the first attempt, to our knowledge, to examine character strengths in individuals across a wide range of disability and chronic condition groups around the world. Growing research has suggested that positive approaches to psychological treatment (such as increasing awareness and usage of character strengths) in individuals with disabilities may be a powerful asset in meeting therapeutic goals and increasing quality of life and wellbeing (8, 11, 25, 29). An alternative to deficit-based methods, which attempt to reduce negative behaviors or symptoms associated with a given disability, character strengths provide a language with which individuals can focus on the aspects of themselves that potentially benefit themselves and society (25). The current study used a well-validated and widely-used classification system and its measurement tool, the *VIA Inventory of Strengths*, in a large international sample across multiple disability types, including emotional conditions and disabilities.

One of the strengths of the study was the inclusion of individuals with physical, cognitive, and emotional disabilities. In addition, disabilities occurring at different developmental stages of life are represented in the sample. For example, intellectual disabilities, like autism, constitute disabilities that emerge relatively early in life and have an enduring presence. The character strengths of individuals with these disabilities might differ compared to individuals with more acute or sudden/adult-onset disabilities, like a traumatic brain injury. Interestingly, we found that commonly reported character strengths in individuals with disabilities include love of learning, honesty, appreciation of beauty and excellence, kindness, and fairness. We found that the least commonly reported strengths in our disability sample included self-regulation, perseverance, zest, spirituality, and prudence. A previous study (27) found the top five strengths were honesty, kindness, fairness, humor, and gratitude, and the bottom five strengths were forgiveness, humility, spirituality, zest, and self-regulation in people with multiple sclerosis. In another study, authors found that the most common character strengths were curiosity, fairness, kindness, judgment, honesty, and leadership, while the least common character strengths were zest, prudence, perseverance, humility, hope, self-regulation, and spirituality in people with dyslexia (37). These results are partially consistent with our findings; however, it is also important to highlight that the most and least common character strengths may change based on disability groups.

Generally, individuals within the TBI group rated their strengths higher overall than other disability groups. For example, the TBI group's endorsements of creativity, curiosity, love of learning, bravery, honesty, perseverance, zest, love, social intelligence, fairness, leadership, prudence, self-regulation, gratitude, hope, and spirituality were significantly higher compared to other disability groups. The only character strength in which the TBI group was lower than others was teamwork, in which they were significantly lower than the MDG group, but significantly higher than IDG group. No significant differences were observed between TBI and other disability groups in judgement, perspective, kindness, forgiveness, humility, appreciation of beauty, excellence, and humor. These findings may provide some interesting avenues of future research in the TBI field. Given that individuals with TBI can often experience mood issues (38, 39), reduced quality of life (40–42), and reduced wellbeing (43), using character strengths knowledge and awareness appears to be an interesting treatment avenue to address these concerns.

One important consideration is that individuals with TBI can have significant self-awareness issues, including both under- and overestimating their skills and abilities (44–46). Therefore, endorsing strengths higher than other comparison groups may be indicative of this phenomenon. However, it would not be useful to dismiss these endorsements as "self-awareness" discrepancies in the TBI group. Rather, in the future, it may be useful to also assess the strengths of an individual with TBI through the perceptions of a trusted "other" who may give a realistic profile of an individual's strengths (e.g., friends, family). Having both the perception of the client as well as a significant other may elucidate which strengths the person expresses in daily life, which may aid in development of therapeutic goals, and which strengths might be inflated because of their limitations in accurately evaluating their strengths.

Those with emotional disturbances reported lower character strengths than other disability groups, which may reflect the poorer self-esteem and lower self-concept commonly observed in those with depression and anxiety. This lower endorsement of character strengths, however, may also provide an opportunity for clinicians to utilize strength identification in their therapy goals. Those with emotional disturbance may be less aware of strengths and therefore merely the identification of strengths may be a powerful exercise.

Another group with low endorsement of character strengths was the IDG group. There is a growing consensus in the field of intellectual disabilities, including autism, that using only a deficit-based approach when treating individuals with autism can compromise self-esteem and leave individuals unaware of their strengths. Therefore, recently a shift has emerged in the autism field to focus on not only strength-based approaches but character strengths-based approaches (25, 30, 47). Our findings indicated lower strength ratings in this group compared to other disability groups indicates that indeed, strength identification needs bolstering in this group. Interestingly, their love of learning endorsements was higher than other disability groups, which may reflect a commonly reported trait of autism: restricted interests. Specifically, those with autism may seek information about a restricted topic to a greater degree than what is typically observed in others, which is generally referred to as a "symptom" or "challenge." However, reframing this trait as a love of learning may be beneficial as it could help autistic individuals, as well as others, understand how this trait may benefit society as well.

Some strength endorsements may reflect the commonly observed traits in individuals with disabilities. For example, low levels of zest, which was consistently one of the lowest reported strengths of the current study may be correlated with significant fatigue levels observed in individuals with disabilities. Fatigue is one of the most commonly reported symptoms in clinical care in the general population and is one of the most commonly reported symptoms in individuals with illness or disability. Thus, low levels of zest may be related to the significant feelings of fatigue felt by this population. In addition, previous literature reported that zest was one of the lowest five character strengths among university students (48) and people with disabilities (27). While increasing zest may represent a treatment target for positive psychology interventions, it may also be helpful for clinicians to keep in mind that chronic fatigue due to illness, disability, comorbidity, medications, and other reasons may make it difficult for certain disability groups to unilaterally increase their zest and energy levels. Rather, setting goals and working on the strengths of perseverance or self-regulation may be more useful, as they involve making choices to overcome obstacles or making choices (such as conserving energy). Together, these proximal goals may be more realistic for someone suffering from fatigue.

Our study findings may provide some significant clinical implications for the use of character strengths interventions in the fields of rehabilitation, psychiatry, and psychology for people with disabilities and chronic conditions. Previous research has demonstrated positive associations between character strengths and subjective health status (49). In a cross-cultural longitudinal study, researchers found that using character strengths is not only beneficial for self-perceived physical health when going through difficult situations, but using strengths is also for enhancing meaning in life, social connectedness, and mental health (50). Given the association between character strengths and health outcomes, clinicians may include interventions such as *using signatures in a new way* or *identifying signature strengths* (51) and *strengths reframing* and the *aware-explore-apply model of strengths* (25) when working with people with disabilities. By helping people with disabilities and chronic conditions identify and utilize their personal character strengths, this may potentially improve their perceived health, psychosocial functioning, and quality of life.

In addition, given this is an international study with multiple countries and disabilities [we consider each disability category as a cultural subgroup (e.g., deaf culture)], it is important to consider cross-cultural and demographic differences in character strengths. If each disability subgroup is considered a cultural subgorup, we suggest each disability group may, on average, have different top and bottom character strengths. For example, people with physical disabilities may experience or express character strengths different compared to people with psychiatric disabilities, just as individuals from different countries and cultures may express character strengths in a different ways reflecting their culture.

Positive psychiatry and psychology aims to examine positive attributes and strengths (10). Besides, positive psychiatry researchers focuses on protective psychosocial factors in chronic conditions. Given our research (a) identifies and describes character strengths in people with chronic conditions, including emotional conditions and (b) demonstrates the top and bottom character strengths among different disability subgroups, findings from this study may contribute to clinical and research practice. This research will help health professionals understand what character strengths are being used among people with different disabilities, which could be helpful in developing tailored and personalized interventions.

There are several limitations that should be considered in this study. The study comprised a convenience sample of individuals with self-reported disabilities, and some participants may not have accurately reported their disability status. As functional and cognitive abilities were not directly assessed, participants' responses may not accurately reflect their perceived character strengths and virtues when navigating an online survey. Further, the ability to complete the survey (and even have access to the survey) assumes that we may have recruited a higher functioning sample; however, there was no way to evaluate this concern. We interpreted the findings by considering that people with learning disabilities, intellectual disabilities, and TBI may have experienced difficulties understanding some concepts and questions. The majority of participants were women, had at least a bachelor's degree, and were employed, which could also limit the generalizability of this study's findings to the general disability population. Another limitation in this study was that participants were categorized into eight disability groups. A more systematic way of categorizing various disabilities could be beneficial. Also, some specific disability types may have been left out and not enough participants were present in different countries for us to formally model between-country variation in the disability group differences that we observed. Future studies are warranted to further examine character strengths in people with disabilities around the globe. We interpreted the findings considering the demographic characteristics of the respondents. For example, the majority of participants were in the age range of 25–54. Therefore, we cannot generalize our findings for all age groups. Similarly, the majority of participants were women, which decreases our ability to generalize our findings. Gender differences are especially important given previous research reported that women typically score higher on strengths than men although the top five strengths were similar among men and women (52).

In conclusion, it is important to highlight that we comment on what has been established in this unique data set and also summarize future considerations to be explored although we are aware that there are many important points to be highlighted in this study. Character strengths has been recently examined in different disability populations (3, 8, 25, 53, 54). In addition to other studies, our study provided a greater understanding of character strengths in a heterogeneous international sample of individuals with disabilities. Overall, this sample of people with disabilities reported their top five character strengths as love of learning, honesty, appreciation of beauty and excellence, kindness, and fairness, and reported their bottom five character strengths as self-regulation, perseverance, zest, spirituality, and prudence. Knowing that there is heterogeneity in character strengths across groups gives us a better understanding of the areas that people with different disabilities might thrive and provides clinicians and practitioners with a more nuanced understanding for how to possibly intervene with their clients.

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.

AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2022.863977/full#supplementary-material

REFERENCES

1. World Health Organization [WHO]. *Disability and Health*. (2020). Available online at: https://www.who.int/news-room/fact-sheets/detail/disability-and-health.
2. Bezyak JL, Sabella S, Hammel J, McDonald K, Jones RA, Barton D. Community participation and public transportation barriers experienced by people with disabilities. *Disabil Rehabil.* (2020) 42:3275–83. doi: 10.1080/09638288.2019.1590469
3. Lee B. A serial mediation model of gratitude on life satisfaction in people with multiple sclerosis: the intermediary role of perceived stress and mental health symptoms. *Mult Scler Relat Disord.* (2021) 103421. doi: 10.1016/j.msard.2021.103421
4. Lee B, Tansey TN, Chan F, Bishop M, Hoyt WT, Hancock LM. Exploration of the effects of protective person–environment factors between functional impairments and stress in individuals with multiple sclerosis: mediation and moderation analyses. *Rehabil Couns Bull.* (2022) 65:95–107. doi: 10.1177/00343552211025534
5. Tansey TN, Smedema S, Umucu E, Iwanaga K, Wu JR, Cardoso E, et al. Assessing college life adjustment of students with disabilities: application of the PERMA framework. *Rehabil Couns Bull.* (2018) 61:131–42. doi: 10.1177/0034355217702136
6. Umucu E. Functional limitations and worrying to lose employment among individuals with chronic conditions and disabilities during COVID-19: a hierarchical logistic regression model. *J Vocat Rehabil.* (2021) 54:25–32. doi: 10.3233/JVR-201114
7. Umucu E, Lee B. Examining the impact of COVID-19 on stress and coping strategies in individuals with disabilities and chronic conditions. *Rehabil Psychol.* (2020) 65:193–8. doi: 10.1037/rep0000328
8. Umucu E, Tansey TN, Brooks J, Lee B. The protective role of character strengths in COVID-19 stress and well-being in individuals with chronic conditions and disabilities: an exploratory study. *Rehabil Couns Bull.* (2021) 64:67–74. doi: 10.1177/0034355220967093
9. Seligman MEP, Csikszentmihalyi M. Positive psychology: an introduction. *Am Psychol.* (2000) 55:5–14. doi: 10.1037/0003-066X.55.1.5
10. Jeste DV, Palmer BW, Rettew DC, Boardman S. Positive psychiatry: Its time has come. *J Clin Psychiatry.* (2015) 76:675–83. doi: 10.4088/JCP.14nr09599
11. Wehmeyer ML. The future of positive psychology and disability. *Front Psychol.* (2021) 12:790506. doi: 10.3389/fpsyg.2021.790506
12. Martz E, Hanoch H. *Coping with Chronic Illness and Disability: Theoretical, Empirical, and Clinical Aspects*. New York: Springer. (2007). doi: 10.1007/978-0-387-48670-3
13. Martz E, Livneh H. Psychosocial adaptation to disability within the context of positive psychology: findings from the literature. *J Occup Rehabil.* (2016) 25:4–12. doi: 10.1007/s10926-015-9598-x
14. Wright BA. *Physical Disability: A Psychosocial Approach*. 2nd ed. New York: Harper and Row (1983). doi: 10.1037/10589-000
15. Chou CC, Chan F, Phillips B, Chan JYC. Introduction to positive psychology in rehabilitation. *Rehabilit Res Policy Educ.* (2013) 27:126–30. doi: 10.1891/2168-6653.27.3.126
16. Edwards KA, Alschuler KA, Ehde DM, Battalio SL, Jensen MP. Changes in resilience predict function in adults with physical disabilities: a longitudinal study. *Arch Phys Med Rehabil.* (2017) 98:329–36. doi: 10.1016/j.apmr.2016.09.123
17. Madan S, Pakenham KI. The stress-buffering effects of hope on adjustment to multiple sclerosis. *Int J Behav Med.* (2014) 21:877–90. doi: 10.1007/s12529-013-9384-0
18. Sanchez J, Muller V, Chan F, Brooks JM, Iwanaga K, Tu WM, et al. Personal and environmental contextual factors as mediators between functional disability and quality of life in adults with serious mental illness: a cross-sectional analysis. *Qual Life Res.* (2019) 28:441–50. doi: 10.1007/s11136-018-2006-1
19. Umucu E, Villegas D, Viramontes R, Jung H, Lee B. Measuring grit in veterans with mental illnesses: examining the model structure of grit. *Psychiatr Rehabil J.* (2020) 44:87–92. doi: 10.1037/prj0000420
20. Lee B, Kaya C, Chen X, Wu JR, Iwanaga K, Umucu E, et al. The buffering effect of character strengths on depression. *Eur J Health Psychol.* (2020) 26:101–9. doi: 10.1027/2512-8442/a000036
21. Niemiec RM. Finding the golden mean: the overuse, underuse, and optimal use of character strengths. *Couns Psychol Q.* (2019) 32:453–71. doi: 10.1080/09515070.2019.1617674
22. Park N, Peterson C, Seligman MEP. Strengths of character and well-being. *J Soc Clin Psychol.* (2004) 23:603–19. doi: 10.1521/jscp.23.5.603.50748
23. Peterson C, Seligman MEP. *Character Strengths and Virtues: A Classification and Handbook*. Oxford University Press (2004).
24. Dahlsgaard K, Peterson C, Seligman ME. Shared virtue: the convergence of valued human strengths across culture and history. *Rev Gen Psychol.* (2005) 9:203–13. doi: 10.1037/1089-2680.9.3.203
25. Niemiec RM, Shogren KA, Wehmeyer ML. Character strengths and intellectual and developmental disability: a strengths-based approach from positive psychology. *Educ Train Autism Dev Disabil.* (2017) 52:13–25.
26. Shogren KA, Shaw LA, Raley SK, Wehmeyer ML, Niemiec RM, Adkins M. Assessing character strengths in youth with intellectual disability: reliability and factorial validity of the VIA-Youth. *Intellect Dev Disabil.* (2018) 56:13–29. doi: 10.1352/1934-9556-56.1.13
27. Smedema SM. An analysis of the relationship of character strengths and quality of life in persons with multiple sclerosis. *Qual Life Res.* (2020) 29:1259–70. doi: 10.1007/s11136-019-02397-1
28. Hanks RA, Rapport LJ, Waldron-Perrine B, Millis SR. Role of character strengths in outcome after mild complicated to severe traumatic brain injury: a positive psychology study. *Arch Phys Med Rehabil.* (2014) 95:2096–102. doi: 10.1016/j.apmr.2014.06.017
29. Umucu E, Wu J-R, Sanchez J, Brooks JM, Chiu C-Y, Tu W-M, et al. Psychometric validation of the PERMA-profiler as a well-being measure for student veterans. *J Am Coll Health.* (2020) 68:271–7. doi: 10.1080/07448481.2018.1546182
30. Kirchner J, Ruch W, Dziobek I. Brief report: character strengths in adults with autism spectrum disorder without intellectual impairment. *J Autism Dev Disord.* (2016) 46:3330–7. doi: 10.1007/s10803-016-2865-7
31. McGrath RE. *Technical report: The VIA Assessment Suite for Adults: Development and initial evaluation (rev. ed.)*. Cincinnati, OH: VIA Institute on Character (2019).
32. McGrath RE, Wallace N. Cross-validation of the VIA inventory of strengths-revised and its short forms. *J Pers Assess.* (2021) 103:120–31. doi: 10.1080/00223891.2019.1705465
33. Signorell. *DescTools: Tools for Descriptive Statistics*. R package version 0.99.42. (2021).
34. Alberti. *GmAMisc: 'Gianmarco Alberti' Miscellaneous*. R package version 1.2.0 (2021). Available online at: https://CRAN.R-project.org/package=GmAMisc.
35. Kassambara. *ggpubr: 'ggplot2' Based Publication Ready Plots*. R package version 0.4.0 (2020). Available online at: https://CRAN.R-project.org/package=ggpubr.

36. R Core Team. *R: A Language and Environment for Statistical Computing*. R Foundation for Statistical Computing, Vienna, Austria (2021). Available online at: https://www.R-project.org/.
37. Kannangara CS, Carson J, Puttaraju S, Allen RE. Not all those who wander are lost: examining the character strengths of dyslexia. *Glob J Intellect Dev Disabil.* (2018) 4:86–93. Available online at: https://juniperpublishers.com/gjidd/pdf/GJIDD.MS.ID.555648.pdf
38. Hoofien D, Gilboa A, Vakil E, Donovick PJ. Traumatic brain injury (TBI) 10? 20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain Injury.* (2001) 15:189–209. doi: 10.1080/02699050130005659
39. Scholten AC, Haagsma JA, Cnossen MC, Olff M, Van Beeck EF, Polinder S. Prevalence of and risk factors for anxiety and depressive disorders after traumatic brain injury: a systematic review. *J Neurotrauma.* (2016) 33:1969–94. doi: 10.1089/neu.2015.4252
40. Draper K, Ponsford J, Schönberger M. Psychosocial and emotional outcomes 10 years following traumatic brain injury. *J Head Trauma Rehabil.* (2007) 22:278–87. doi: 10.1097/01.HTR.0000290972.63753.a7
41. Forslund MV, Roe C, Sigurdardottir S, Andelic N. Predicting health-related quality of life 2 years after moderate-to-severe traumatic brain injury. *Acta Neurol Scand.* (2013) 128:220–7. doi: 10.1111/ane.12130
42. Hawthorne G, Gruen RL, Kaye AH. Traumatic brain injury and long-term quality of life: findings from an Australian study. *J Neurotrauma.* (2009) 26:1623–33. doi: 10.1089/neu.2008.0735
43. Payne L, Hawley L, Ketchum JM, Philippus A, Eagye CB, Morey C, et al. Psychological well-being in individuals living in the community with traumatic brain injury. *Brain Injury.* (2018) 32:980–5. doi: 10.1080/02699052.2018.1468573
44. Bivona U, Riccio A, Ciurli P, Carlesimo GA, Delle Donne V, Pizzonia E, et al. Low self-awareness of individuals with severe traumatic brain injury can lead to reduced ability to take another person's perspective. *J Head Trauma Rehabil.* (2014) 29:151–71. doi: 10.1097/HTR.0b013e3182864f0b
45. Goverover Y, Chiaravalloti N. The impact of self-awareness and depression on subjective reports of memory, quality-of-life and satisfaction with life following TBI. *Brain Injury.* (2014) 28:174–80. doi: 10.3109/02699052.2013.860474
46. Pettemeridou E, Kennedy MR, Constantinidou F. Executive functions, self-awareness and quality of life in chronic moderate-to-severe TBI. *Neurorehabilitation.* (2020) 46:109–18. doi: 10.3233/NRE-192963
47. Carter EW, Boehm TL, Biggs EE, Annandale NH, Taylor CE, Loock AK, et al. Known for my strengths: positive traits of transition-age youth with intellectual disability and/or autism. *Res Pract Persons Severe Disabil.* (2015) 40:101–9. doi: 10.1177/1540796915592158
48. Zhang Y, Chen M. Character strengths, strengths use, future self-continuity and subjective well-being among Chinese university students. *Front Psychol.* (2018) 9:1040. doi: 10.3389/fpsyg.2018.01040
49. Proyer RT, Gander F, Wellenzohn S, Ruch W. What good are character strengths beyond subjective well-being? The contribution of the good character on self-reported health-oriented behavior, physical fitness, and the subjective health status. *J Positive Psychol.* (2013) 8:22–32. doi,: 10.1080/17439760.2013.777767
50. Weziak-Bialowolska D, Bialowolski P, VanderWeele TJ, McNeely E. Character strengths involving an orientation to promote good can help your health and well-being. Evidence from two longitudinal studies. *Am J Health Promot.* (2021) 35:388–98. doi: 10.1177/0890117120964083
51. Seligman MEP, Steen TA, Park N, Peterson C. Positive psychology progress: empirical validation of interventions. *Am Psychol.* (2005) 42:874–84. doi: 10.1037/0003-066X.60.5.410
52. Linley PA, Maltby J, Wood AM, Joseph S, Harrington S, Peterson C, et al. Character strengths in the United Kingdom: The VIA inventory of strengths. *Pers Individ Differ.* (2007) 43:341–51. doi: 10.1016/j.paid.2006.12.004
53. Umucu E, Lo CL, Lee B, Vargas-Medrano J, Diaz-Pacheco V, Misra K, et al. Is gratitude associated with suicidal ideation in veterans with mental illness and student veterans with PTSD symptoms? *J Nervous Mental Dis.* (2022) 210:26–31. doi: 10.1097/NMD.0000000000001406
54. Lee B, Pfaller J, Iwanaga K, Chen X, Wu JR, Chan F. Core self-evaluations as a mediator of the relationship between stress and quality of life in women with multiple sclerosis. *J Vocat Rehabil.* (2020) 52:137–44. doi: 10.3233/JVR-191066

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SYSTEMATIC REVIEW
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Exploring the Personal Recovery Construct in Bipolar Disorders: Definition, Usage and Measurement. A Systematic Review

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Personal recovery from psychiatric disorders is a journey toward a satisfying and hopeful life despite the possible persistence of symptoms. This concept has gained interest and become an increasingly important goal in mental health care programmes. Personal Recovery is well described in the context of severe mental illnesses in general, but little is known about this journey in bipolar disorders and the factors underlying it. A systematic review was conducted according to the PRISMA recommendations, focusing on studies exploring personal recovery in bipolar disorder specifically. The latter have integrated a comprehensive approach to the concept, the existing means of measurement or have explored the levers of recovery in care. Twenty-four articles were selected, including seven qualitative, 12 observational, and five interventional studies. The Bipolar Recovery Questionnaire was the only scale developed *de novo* from qualitative work with bipolar people. Personal recovery did not correlate very closely with symptomatology. Some elements of personal recovery in bipolar disorder were similar to those in other severe mental illnesses: meaning in life, self-determination, hope, and low self-stigma. Specific levers differed: mental relationships with mood swings, including acceptance and decrease in hypervigilance, and openness to others, including trust and closeness. The studies highlighted the role of caregiver posture and the quality of communication within care, as well as the knowledge gained from peers. The choice to exclude articles not focused on bipolar disorder resulted in the provision of very specific information, and the small number of articles to date may limit the scope of the evidence. New components of personal recovery in bipolar disorder emerged from this review; these components could be taken into account in the construction of care tools, as well as in the caregiving posture. Strengthening skills of openness to others could also be a central target of recovery-focused care.

Keywords: bipolar disorder, personal recovery, mental health recovery, patient-reported outcome measures, recovery-oriented practice, systematic review

INTRODUCTION

Traditional psychiatry usually considers recovery to be a clinical or functional outcome. Gradually, the concept of "personal recovery" (PR) has emerged and gained interest in the field of psychiatric disorders. PR is distinct from clinical and functional recovery: it refers to a psychological process of adjustment to a disorder rather than to a reduction in symptoms (clinical recovery) or functional improvement (functional recovery). These concepts of clinical recovery, functional recovery and PR are distinct but related (1). This construct was first developed by patients themselves (2, 3) through first-person accounts. The possibility of a favorable outcome of severe psychiatric illnesses, despite the possible persistence of certain symptoms, subsequently aroused the interest of clinicians and public authorities. Indeed, it was found that patients with severe mental illnesses (SMIs), such as bipolar disorder (BD), expressed dissatisfaction with the current primary targets of treatment; they wanted caregivers to place more emphasis on PR outcomes (3).

Anthony et al. proposed the following definition of PR in 1993: "*a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles… a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness*" (4). Through a literature review in 2011, Leamy et al. created the "CHIME framework", a conceptual framework based on five processes that were identified as important factors of PR: connectedness, hope and optimism about the future, identity, meaning in life, and empowerment in severe mental health problems (5).

PR- and recovery-oriented practices have become important in mental health care and are developing based on the initiative of public authorities and at the request of users and families. A review of PR in BD was carried out by Jagfeld et al. in 2021 (6) and focused on qualitative studies. It showed a greater importance of self-management of the disease and medication, as well as socially significant roles such as work and parenthood, and brought a notion of tension inherent in the RA process. This tension would require an active process of acceptance.

A recent scoping review of systematic reviews in PR identified two needs: to better understand the process of PR, in particular the underlying mechanisms of PR, and to adapt the CHIME conceptual framework to the characteristics of specific populations, in particular those with mood disorders (7). This conceptual framework has been studied in the context of schizophrenia or SMIs in general; nevertheless, little is known about factors contributing specifically to PR in people with BD.

It is important to pay attention to psychological and environmental factors underlying PR in BD specifically. Indeed, it is likely that some elements of PR in BD are found in SMIs in general, while others may be more specific to BD. The mood fluctuations constitutive of BD and the relative need for balance may alter the constituents and determinants of PR; for example, high levels of optimism, involvement in meaningful activities, social interaction and self-confidence may be related to an imbalance in the disorder, which may not be the case for people with psychosis (8).

The present systematic review sought to address the following question: What is the current evidence regarding the process of PR in people with BD?

METHODS

Search Strategy

A systematic review was conducted to identify all relevant publications using PsychINFO, MEDLINE, ScienceDirect. We complied with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) (9). The search terms used were "bipolar disorder" associated with "personal recovery" or with "mental health recovery". Indeed, both of the latter two terms were found to describe the process of PR in published studies. These terms needed to appear in title, abstract or keywords. Duplicates were eliminated.

Figure 1 presents the flowchart illustrating the search and identification of relevant articles.

Eligibility Criteria

Relevant articles were selected based on the following inclusion criteria: peer-reviewed studies available in English or French with the full text available that were published prior to 1 May 2021 and that focused on PR in people suffering from BD. No backward time constraints were used. Three types of studies were selected: qualitative studies, interventional studies, and observational studies.

Articles that met the following exclusion criteria were excluded: first-person accounts and case reports, study protocols that had no results yet available, studies of multiple psychiatric disorders, and studies not specifically focusing on PR.

Article Selection

First, articles were selected based on their titles and abstracts. Second, the full texts of all of the included articles were read. The authors (MCE and MD) performed this work independently and blindly using the same bibliographic search criteria. In the event of disagreement, the relevant articles were discussed with a third author (BS). Additional publications were found by reviewing the citations of the included papers.

Data Extraction

The articles were classified into three types: qualitative, interventional and observational studies.

Data extraction was differentiated according to the type of article's pre-established grids.

For all studies, data were extracted from the articles and reported by data type as well as country of the research group, type of study, sample size, scale assessing PR/description of PR, correlated dimensions or outcomes, and significant findings/main themes.

Data Analysis and Synthesis

Thematic analysis was conducted through a line-by-line analysis of included papers coding relevant text. The analysis of the data was carried out using a mainly inductive approach, without a pre-established thematic grid.

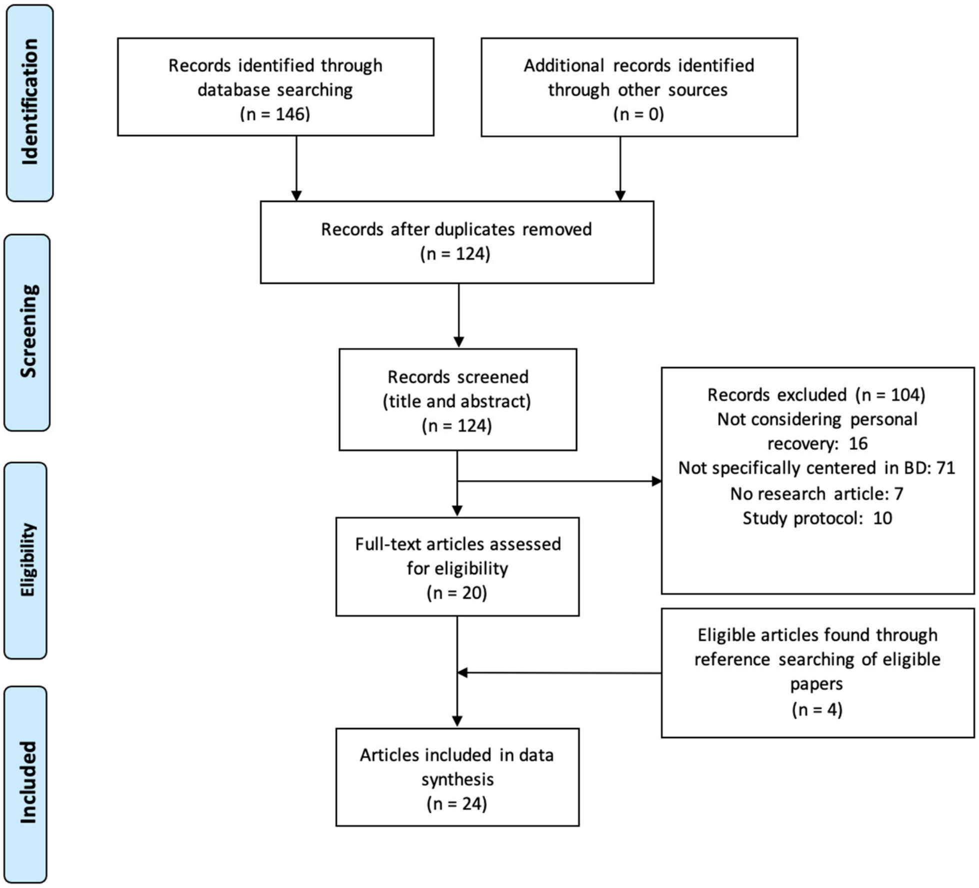

FIGURE 1 | Flowchart.

The identified articles were analyzed using a thematic analysis that incorporated the following themes: identification of how PR was measured in the various works, a comprehensive approach to PR in BD, and how care may contribute to PR. Through these three themes, we presented the results of different types of work: qualitative studies that described this process, as well as a number of observational and interventional studies exploring the measurement of PR and the factors involved in this process. Additionally, we presented the various interventional studies that targeted PR as an outcome to better understand the evidence for care tools that might contribute to it.

For the content analysis of the qualitative studies, themes and subthemes were extracted from all studies.

The level of scientific evidence of the published studies was classified according to a decreasing level of scientific evidence, in accordance with the guide for the analysis of the literature and the gradation of recommendations, published by the Haute Autorité en Santé (HAS) in 2013 (10). This grid was adapted from the Sackett score (11).

RESULTS

Study Characteristics

Twenty-four articles met the inclusion criteria (flowchart in **Figure 1**). The study characteristics and main results are presented in tables according to the types of studies: qualitative studies (**Table 1**), observational studies (**Table 2**), and interventional studies (**Table 3**).

Even though no backward time constraints were used in the selection of articles, no articles published prior to 2010 met the selection criteria with these keywords.

Study Types

Among the 24 articles selected, we found seven qualitative studies, including one on a core outcome set (COS); 12 observational studies; and five interventional studies, including two randomized controlled trials (RCTs).

Qualitative studies consisted of the systematic analysis of the verbatim narratives of people suffering from BD, collected during individual interviews or focus groups; this analysis allowed us to group the elements of the discourse into themes and subthemes to draw out their meaning. The techniques used were in-depth individual interviews (12, 14, 16, 17) or focus groups (13, 15). The number of subjects included varied from 11 (12) to 56 (15).

Observational studies involved different data collected through objective clinical or sociodemographic indicators and/or subjective psychometric scales at a defined time. Among the 12 observational studies collected, three were validation studies of psychometric scales (8, 24, 25).

TABLE 1 | Characteristics and main results of qualitative studies included ($N = 7$).

Research group	Country	Intervention/ approach	Methodology	Sample size	Findings
Mansel et al. (12)	UK	Individual in-depth interview	Qualitative study	$N = 11$	Differences between:Ambivalent approaches (avoiding mania, taking medication, identity following diagnosis) Helpful approaches (understanding, life-style fundamentals, social support, and social change)
Todd et al. (13)	UK	Focus Groups	Qualitative study	$N = 12$	PR is not about being symptom free PR requires taking responsibility for your own wellness Self-management is a key component Overcome barriers to recovery: negativity, stigma and taboo
Veseth et al. (14)	Norway	Individual in-depth interview	Qualitative study	$N = 13$	Handling ambivalence about letting go of manic states; Finding something to hang on to when the world is spinning around; Becoming aware of signals from self and others; Finding ways of caring for oneself.
Maassen et al. (15)	Netherlands	Focus groups	Qualitative study	$N = 56$ (7FG)	To formulate the care needs for people with BD Need help for acceptance and find self-care strategies
Crowe et al. (16)	New Zealand	Individual in-depth interview	Qualitative study	$N = 30$	What was helpful in psychotherapy? What do they use 5 years later for their own recovery? Facilitate self-awareness and understanding of BD. Develop self-care strategies, and sense of agency. Emphasize hope and optimism
Tse et al. (17)	China	In-depth interviews	Qualitative study	$N = 32$	How to share Knowledge? The importance of how knowledge has been shared rather than the type of knowledge (technical vs expert-by-experience). – Empathy – Hope-instilling manner – Role models
Retzer et al. (18)	UK	In-depth interviews, Focus groups and modified Delphi process	Qualitative study	$N = 50$ (Outcomes); $N = 14$ (Delphi process)	Construction of a COS (core outcome set) of 11 outcomes

Five interventional studies were included in this review. Only two articles reported on RCTs, whereas three reported on pre-post therapy uncontrolled trials.

Quality Appraisal of Studies Included

The observational and interventional studies had a rather low level of scientific evidence (level 4), with the exception of the two RCTs (level 2).

How Is PR Measured in BD?

In this review, we were interested in the measurement tools for PR used with people with BD. In total, we identified four scales assessing PR.

Only two of these PR scales were specifically validated for BD: the Bipolar Recovery Questionnaire (BRQ) (8) and the Questionnaire of Personal Recovery (QPR) (24).

The BRQ was the only scale that has been developed *de novo* from qualitative work among people suffering from BD (13). Despite a moderate sample size (60 subjects), the scale showed good internal consistency (alpha = 0.875). External construct validity was established by incremental differences in personal growth, functioning, mood symptoms and wellbeing. The validation study of the BRQ (8) showed good test-retest reliability at 1 month ($r = 0.866$, $p < 0.001$). The sample size did not permit the exploration of its factor structure and dimensions.

The QPR was developed from the CHIME framework. The scale was initially created and validated for PR in schizophrenia

TABLE 2 | Characteristics and main results of observational studies.

Research group	Country	Intervention/ approach	Methodology	Sample size	Scales assessing PR	Other outcomes	Findings	Quality appraisal of studies (Level I-IV)
Jones et al. (8)	UK	Online survey	Cross sectional online study + Test-retest 1 month	$N = 60$	BRQ	Symptoms: MRS, HDRS, BDI-II, ISS Functioning: PSP, MOS SF12 Post Traumatic Growth Inventory: PTGI	Validation study of the BRQ scale: reliability, internal consistency, validity. Correlations: Functioning and wellbeing more than symptoms. Post-traumatic growth. Coping and confidence in one's resources	IV
Tse et al. (19)	China	Clinical Interviews	Cross sectional study	$N = 75$	SRS	Recovery-Elements Assessment Questionnaire-patient version (REAQ) Organizational Climate Subscale (OCS) Symptoms (HAM-D- YMRS)	Correlations with latter stages of PR: ≪ Respect, hope, and self-directed empowerment ≫ dimension of REAQ, ≪ meaningful role ≫ dimension Older age Early first diagnosis, Binge drinking history	IV
Tse et al. (20)	China	Clinical Interviews	Cross sectional study	$N = 75$	SRS	Residential status employment status (i.e. functional recovery) Symptoms (HAM-D- YMRS) Elements Assessment Questionnaire-patient version (REAQ)	Correlations with latter stages of PR: Female, being married, Functional recovery and personal recovery are correlated (rs.21–0.28), but far from identical. No significant correlations be-tween SRS scores, residential status, and employment status.	IV
Grover et al. (21)	India		Cross-sectional study	$N = 185$	RAS	Internalized Stigma of Mental Illness Scale (ISMIS), Brief Religious coping scale (RCOPE), Duke University Religiosity Index (DUREL), Religiousness Measures Scale (RMS), Symptoms (HDRS, YMRS) Functioning (GAF)	Correlations: Negative correlation with residual depressive symptoms Positive with: Low internalized stigma High level of functioning Higher use of positive religious coping mechanisms Employment status and high income. No correlation with sociodemographic variables	IV
Dodd et al. (22)	UK	Online survey	Cross sectional online study	$N = 87$	BRQ	Mood symptoms Appraisals and beliefs about mood swings	Correlations PR with: Symptoms: negative correlations with current depression, positive with recent depression, no correlation with mania.	IV

(Continued)

TABLE 2 | Continued

Research group	Country	Intervention/ approach	Methodology	Sample size	Scales assessing PR	Other outcomes	Findings	Quality appraisal of studies (Level I-IV)
						Positive beliefs about mood swings correlated with High PR/ negative illness models linked to poor PR No correlation with: age, gender, years since diagnosis, medication use, educational level Positive correlation between PR and being in work.		
Etchezarraga et al. (23)	Spain	Online survey; T1-T2 at 6 months	Cross-sectional and longitudinal online study	*N* = 125 (baseline); *N* = 60 (6 months)	BRQ	Resilience Questionnaire for Bipolar Disorder [RBD] Symptoms (ISS) Functioning (Work and Social Adjustment Scale) Quality of Life (Brief-QoL BD)	Correlations PR with: Self-care, self-management and self-confidence (resilience factors of the RBD scale) Self-confidence directly predicted the increase of PR over time. Interpersonal support and self-care indirectly predicted the increase of personal recovery through the mediation of improved self-confidence.	IV
Kraiss et al. (24)	Netherlands	Online survey	Cross sectional online study	*N* = 102	QPR (Questionnaire about the Process of Recovery) 15 items	Well-being (Mental Health Continuum MHC-SF) Short Social Role ParticipationQuestionnaire (S-SRPQ) Symptoms (HADS, ASRM)	Validation study of the QPR scale: reliability, internal consistency, validity. Unidimensional structure. Correlations PR with: Strong positive correlation with wellbeing Positive correlation with social role participation Only weak correlation with manic symptoms.	IV
Kraiss et al. (25)	Netherlands	Online survey	Cross sectional online study	*N* = 107	QPR (Questionnaire about the Process of Recovery) 15 items	Responses to Positive Affect (RPA) Well-being (14-item Mental Health Continuum MHC-SF) Social role participation (S-SRPQ) Symptoms (HADS, ASRM)	Validation study of the QPR scale in which QPR is involved Correlations PR with: Negative correlation with dampening Positive correlation with scores of emotion-focused positive ruminations	IV

(Continued)

TABLE 2 | Continued

Research group	Country	Intervention/ approach	Methodology	Sample size	Scales assessing PR	Other outcomes	Findings	Quality appraisal of studies (Level I-IV)
Dunne et al. (26)	Australia	Online survey	Cross-sectional study	$N = 312$	BRQ	Self-reported depression or mania	Correlations PR with: Positive correlation with: Quality of Social support Being employed Higher education Negative correlation with: Depressive or manic symptoms.	IV
Mezes et al. (27)	UK	Online survey; T1-T2 at 6 months	Cross-sectional and longitudinal online study	$N = 107$ (baseline); $N = 90$ (6 months)	BRQ	Number of episodes (SCID) Symptoms (CES-D, AMRS) Cognitive Vulnerability Model. (IDQ, HIQ, DAS-24, Response style theory Response Style Questionnaire (RSQ) revised version Behavioral Activation System (BAS) Dysregulation Model. Impulsivity (BIMP)	Correlations PR with: Being in employment/meaningfully occupied predict improved PR at a six-month follow-up Cognitive vulnerability model: negative self-dispositional appraisals are associated with lower PR; high adaptative coping and risk-taking correlated with higher PR.	IV
Wynter et al. (28)	Australia	Online survey	Cross-sectional study	$N = 393$	BRQ	Parental and intimate relationship functioning: Social Adjustment Scale Self-Report (SAS-SR)	Correlations PR with: Being employed Level of education Greater parental functioning and intimate functioning No correlation with: child at home, or living with an intimate partner	IV
Kraiss et al. (29)	Netherlands	Online survey	Cross-sectional study	$N = 209$	QPR	Social Role Participation (S-SRPQ) Symptom anxiety-depression (HADS-A), manic ASRM. Positive emotion regulation (RPA)	Correlations PR with: Satisfaction with social roles = the strongest correlate of personal recovery Dampening: small negative correlation Emotion-focused Positive ruminations: positive correlation Negative correlation with anxiety symptoms; positive correlation with manic symptoms	IV

$N = 12$.

TABLE 3 | Characteristics and main results of interventional studies ($N = 5$).

Research group	Country	Intervention/ approach	Methodology	Sample size	Scales assessing PR	Other outcomes	Findings	Quality appraisal of studies (Level I-IV)
Todd et al. (30)	UK	Web-based self-management intervention ≪ living with bipolar ≫ LWB	RCT	$N = 122$ LWB+TAU vs.TAU TAU only (waiting list)	BRQ	Quality of Life (QoL) Qol-BD brief WhoQoL bref Internal States Scale (ISS) The Social Adaptation Self-Evaluation Scale (SASS)	The most robust potential treatment effects QoL, recovery and wellbeing The most important effect size (0,7) for Recovery. The existence of an online community appears to play a key role.	II
Jones et al. (31)	UK	Recovery-focused CBT for recent-onset BD	RCT with 15 months follow-up	$N = 67$ BD recent onset (past 5 years) Therapy vs TAU	BRQ	Time to relapse Clinical symptoms QoL Social functioning Medication adherence Therapeutic alliance	Greater improvement in recovery after therapy, sustained at follow-up ($P = 0{,}010$) Time to recurrence was statistically significant for mania and depression ($P<0.006$) No impact on mood or treatment adherence, Nonsignificant trend toward a positive effect on quality of life and social functioning.	II
Jones et al. (32)	UK	10-session group psychoeducation intervention (Mood on Track) MOT	Pre-post therapy	$N = 202$	BRQ	QoL BD, ISS Anxiety, depression, Work and Social Adjustment Scale WASAS	Recovery. BRQ scores improved between pre and post therapy, difference was of medium effect size and statistically significant. QoL and social functioning improved significantly	IV
Richardson et al. (33)	UK	12 weeks group	Pre-post therapy	$N = 23$	BRQ	Self-esteem and stigma: Views on Manic Depression Questionnaire The Brief Illness Perception Questionnaire	Recovery: significant change in scores on the BRQ $p<0.05$ Significant changes on the Brief Illness Perception questionnaire post- group	IV
Enrique et al. (34)	Ireland	Internet-delivered self-management intervention for 10 weeks +TAU "Bipolar Toolkit "	Pre-post therapy	BD; $N = 20$	BRQ	QoL BD Brief Illness Perception Questionnaire (BIPQ) The Internal State Scale [ISS, (35)]	Significant differences for the BRQ ($z = 2.38$, $p = 0.017$).	IV

(36). It was then reduced from 22 to 15 items for a more robust version. Its validation for BD was later performed by Kraiss et al. in 2019 through a cross-sectional survey that included 102 people: the scale showed good internal consistency on a unidimensional scale ($\alpha = 0.92$). Convergent validation measures assessed wellbeing, social role participation, and symptomatology (24).

Other psychometric scales, nonspecific to BD, were used in the studies. The Recovery Assessment Scale (RAS) was chosen by Grover et al. (21) in a psychometric study. The factor structure of the RAS scale was explored by Corrigan et al. (37) in a population of people suffering from SMIs. This scale had previously been used in an Australian study (38) with a population of severely mentally ill people, of whom only 38 were affected by BD. The small sample of BD patients did not allow reliable conclusions to be drawn in this first work. Similarly, the Chinese team of Tse et al. (19, 20) used the Stages of Recovery Scale (SRS), a scale previously developed with a population of people with SMIs in Taiwan. In these two studies, Tse et al. used the SRS in a sample of 75 people suffering from BD, in which Cronbach's alpha for the SRS was 0.95.

At the date of this review, all interventional studies, whether controlled or uncontrolled, have used the BRQ scale. As a result, the BRQ scale has the most evidence in terms of sensitivity to change.

Characteristics of psychometric scales assessing PR in BD are presented in **Table 4**.

Comprehensive Approach to Recovery in BD

Through Qualitative Studies

The first articles identified in this review explored the concept of PR in BD in early 2010. Previously, authors were interested in notions that were restricted to the reduction of clinical symptoms. At that time, the term "recovery" was used, referring to clinical recovery and not to the PR process.

One of the main themes of the thematic analysis of the content of qualitative studies was the concept of PR itself and how people living with BD act in relation to PR.

Within this theme, we identified four subthemes:

- First, in 2012, Todd et al. focused on one general question: What does PR mean to people living with BD?
- Three other subthemes emerged from other studies: mental relationships with mood swings, relationships with other people, and finding ways of caring for oneself.

First subtheme: "What does PR mean to people living with BD?"

In 2012, Todd et al. (13) conducted a series of three focus groups with 12 people suffering from BD, asking them what PR meant for them. Four themes emerged: PR is not about being symptom-free but means living a personally fulfilling life alongside one's condition despite mental health symptoms; PR requires taking responsibility for one's own wellness and necessitates moving away from the traditional medical mode; self-management is considered to be one of the key components of recovery; and there is a need to overcome barriers to recovery, including negativity, stigma and taboo. The findings of Todd et al. contributed to the development of the BRQ scale.

Second subtheme: "Mental relationships with mood swings"

The subtheme of mental relations with mood changes highlighted four concepts that were sources of PR (12, 14):

- Acceptance and progressive tolerance of changes in internal states.
- Less extreme control behaviors and less hypervigilance about manic recurrences, contributing to the development of a more coherent and less dependent self-image.
- Good acceptance of the disorder, allowing self-care.
- The need to manage the ambivalence of letting go of manic states.

PR would thus be made up of an equilibrium between acceptance of the disorder and an appropriate relationship with fluctuating thymic states.

Third subtheme: "Relationships with others"

This theme included three concepts: (1) the fundamental need for a social support network that provides support and companionship and (2) helping relationships in which others can alert the person concerning a weakening of mood in (3) a relationship of trust and guidance (14). Moreover, openness to others was established as key to PR: this concept was framed in terms of engendering "trust" and "closeness" with others (12).

Fourth subtheme: "Finding ways of caring for oneself"

Self-care and self-management were highlighted as central features of PR in people with BD.

The main tools of self-care were discussed as follows: accepting that one has a problem to understand it better, gaining experience through both external sources and personal experiences, and having a balanced lifestyle (12).

Veseth et al. insisted on the need to find a fixed point, something to anchor one's life despite constant fluctuations. According to these authors, becoming aware of signals from oneself or others is also a way of self-care: indeed, self-care practices are closely linked to the human and material environment. Furthermore, the authors stressed the importance of agency and responsibility: all participants in their study made "the choice to get better" (14).

A synthesized presentation of the qualitative results and links with elements of observational studies is presented in **Figure 2**.

Observational Studies Using Psychometric Tools for a Comprehensive Approach to PR

The observational studies used other means to understand the PR process in BD. These studies highlighted three types of factors associated with effective PR in BD by measuring the correlation between scores on PR scales and measures of social, clinical, psychological factors.

Social and Professional Factors Associated With PR

Notably, sociodemographic variables such as age and gender did not predict PR in BD (8, 13, 21), but a higher level of education was found to favor PR (26).

Having a meaningful job and having a high level of satisfaction with social roles were the most positively correlated with PR

TABLE 4 | Characteristics of scales assessing PR in BD.

Scale	Number of items	Internal consistency	Dimensions	Specific to BD?	Sample size of validation study	Particularities of the scale
BRQ	36	Good (α = 0.875) + Good test-retest reliability at 1 month (r = 0.866, $p < 0.001$)	Not documented	YES	*N* = 60	Specifically constructed for people with BD
QPR	22 items, secondly reduced to 15 items	Good (α = 0.92).	22 items version 2 subscales – Intrapersonal α =0,94 – Interpersonal α =0,77) – 15 items version: unidimensional (α =0,933)	NO; the 15-item version was validated in BD	*N* = 335 (15 items version)	Short and unidimensional scale
RAS	41		5 dimensions – Personal confidence and hope (α =0,87) – Willingness to ask for help (α =0,84) – Goal and success orientation (α =0,82) – Reliance to others (α =0,74) – No domination by symptoms (α =0,74)	NO	*N* = 1824	The most widely used PR scale in SMIs
SRS	45		3 dimensions considering PR as a process: Regaining autonomy, Disability management/Taking responsibility, Sense of hope + 3 dimensions considering PR as an outcome: Overall wellbeing, Social functioning/role performance, Helping others	NO	*N* = 471	Developed specifically for chinese-speakers people suffering from SMIs

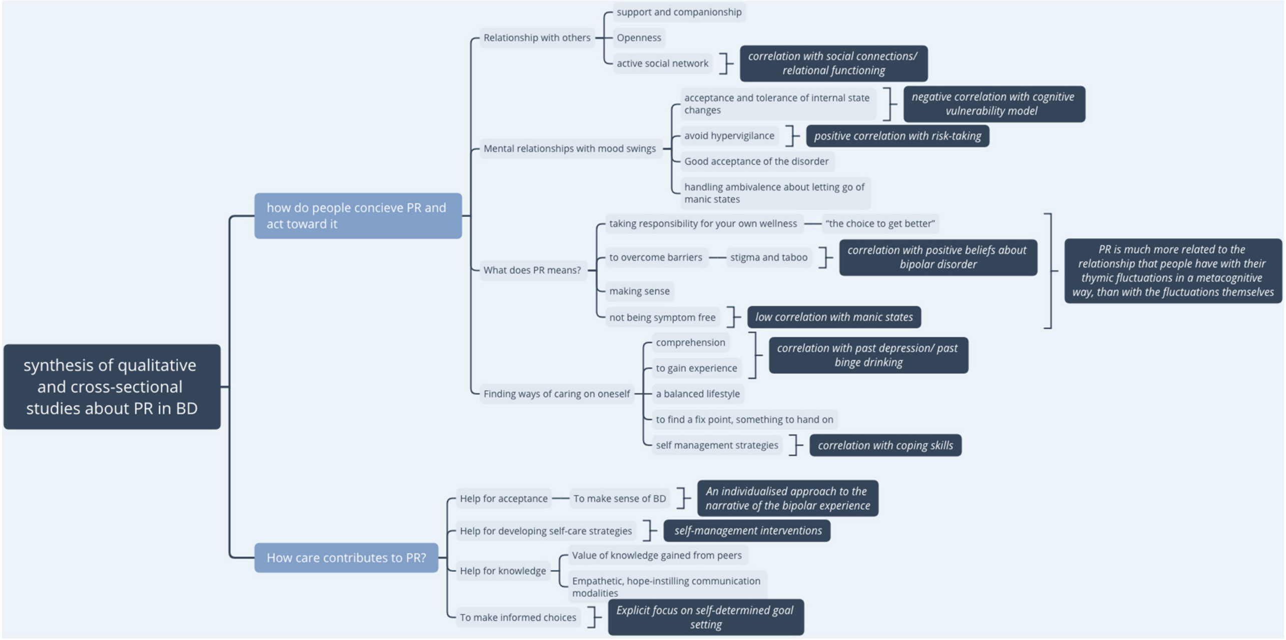

FIGURE 2 | Synthesis of qualitative and cross-sectional studies.

(29). Employment was highly associated with PR (20–22) and predictive of PR at a six-month follow-up (39).

The quality of social support, particularly the frequency of social connections, was also associated with high PR (26). The quality of relational functioning with close relatives, more than the family situation itself, was positively correlated with the level of PR (28).

Clinical Factors Correlated With PR in BD

Different studies have shown a significant negative correlation with current depression and anxiety symptoms (8, 21, 22) but a positive correlation with a past experience of depression (8, 22).

There was no correlation with the intensity of manic symptomatology (21) or only a small positive correlation (22, 24, 25).

Another finding was a positive correlation between PR and a young age of diagnosis of BD (19), which was not found by Grover et al. Finally, a history of binge drinking was positively correlated with PR (19).

Psychological Factors Associated With PR

Various psychological characteristics were shown to contribute to better PR in people suffering from BD. These characteristics included wellbeing, posttraumatic growth (8), empowerment (19), coping skills including religious values and spirituality (21, 39), and confidence in one's own resources. Low self-stigma, positive beliefs about BD, and good acceptance of mood swings were also associated with PR (22). Additionally, emotion-focused positive ruminations, described as the tendency to respond to positive emotions with recurrent thoughts about positive experiences, were positively correlated with PR (29). Additionally, the level of self-efficacy and self-management skills were related to PR (22).

A higher level of risk-taking was also associated with PR. Risk-taking includes inappropriate but potentially pleasurable activities such as recreational drug use, binge drinking or casual sex (39).

Finally, self-determination was highlighted: the "Respect, Hope, and Self-Directed Empowerment" (RHSE) dimension of the Recovery Elements Assessment Questionnaire (REAQ) was strongly associated with advanced PR. This demonstration reinforced the importance of making informed choices for oneself to facilitate progression to the next stages of PR (19).

In contrast, several factors that inhibit PR were identified. A high level of self-stigma and negative illness models, such as thoughts about uncontrollable mood swings, were correlated with a worse level of PR (21, 22). Higher negative self-dispositional appraisals were associated with lower PR (39). Dampening, which is described as a cognitive strategy of suppression of positive moods to reduce the intensity of positive affect (40), was moderately associated with poor PR (29).

In What Ways Does Care Contribute to PR?

Tools and Modalities of Care Supporting PR in BD

The qualitative studies explored the needs expressed by people suffering from BD to support their PR within the care system.

Three subthemes emerged:

- People expect care to help them accept and find self-care strategies (15). Some experimented with psychotherapies that facilitated self-awareness; it helped to make sense of BD, to understand it better, to develop self-care strategies, and to have a sense of agency (16).
- The value of knowledge gained from peers was highlighted. How knowledge has been shared was more important than the type of knowledge. Empathetic, hope-instilling communication modalities and the embodiment of role models were key (17).

Interventional Studies in Which PR Was an Outcome

These studies provided additional data on the levels of PR in psychiatric care.

PR as an Outcome

This review included five interventional studies, of which two RCTs targeted PR as a primary outcome.

In all of these studies, PR was measured using the BRQ (8) only.

Other outcomes that were targeted by this clinical research were quality of life, social functioning, thymic symptoms and time to relapse, therapeutic alliance, self-esteem and self-stigma.

Type of Therapeutic Interventions Evaluated by These Studies

The different therapeutic interventions studied were web-based self-management interventions (30, 34), a recovery-focused cognitive behavioral therapy (CBT) program (31), a group psychoeducation program (31), and a program combining psychoeducation, CBT and mindfulness (33).

The five published studies that assessed PR as a primary outcome showed significant effectiveness of the interventions for PR. The detailed results of these studies are presented in **Table 3**.

Jones (31) detailed the particularities of the recovery-focused treatment approach that differ from usual modalities of treatments to support recovery. This therapeutic intervention was developed in partnership with lived bipolar experience.

- An explicit focus on self-determined goal setting rather than relapse prevention (31) and a focus on building a personally meaningful life alongside symptoms (30)
- An individualized approach to the narrative of the bipolar experience, rather than the application of a predetermined model of the bipolar experience to all clients
- Freedom to work within the model provided by the client
- An openness to addressing issues of functioning and comorbidity as well as mood issues
- Work with people to abandon self-critical and/or stigmatizing language.

Effects of These Therapeutic Interventions on PR

Jones et al. (31) showed positive effects of their CBT program on PR and on time to relapse, maintained at 15 months follow-up. This impact on relapse was not associated with a change in residual mood symptoms that were not improved by the intervention. The authors postulated that improvement in PR may itself be a possible mechanism for improving relapse: as the BRQ includes self-care and understanding of mood experiences, these may play a role in relapse prevention. The same team (32) showed significant positive effects on PR of a 10-session psychoeducation intervention program "Mood on track", with a medium effect size ($d = 0.52$); these results were confirmed by Richardson for a similar 12-session CBT-based psychoeducation program (33).

Self-management tools also seemed to improve PR in people with BD. Todd et al. conducted an RCT showing the benefit of a self-management program, predominantly on PR, with a mean effect size of 0.7 across all outcomes (30). Enrique et al. (34) confirmed these results with a pre-post therapy study with a smaller sample size ($N = 20$) but using a mixed methodology, combining quantitative results and semistructured interviews with patients and carers. The qualitative interviews indicated that patients felt they had improved their awareness and understanding of their illness and felt more empowered.

DISCUSSION

General Discussion

This work is, to the best of our knowledge, the first systematic review collecting different types of studies centered on PR in BD, including qualitative works, observational studies, and interventional studies. A review by Murray et al. (41) focused on psychosocial approaches to supporting PR in BD but did not explore the process itself. In addition, Jagfeld et al. recently published a systematic review of only qualitative works centered on PR in BD (6).

This review highlighted several specific characteristics of PR in people suffering from BD. The results of the different studies collected were generally consistent: the studies using psychometric tools confirmed the data of the studies using a qualitative methodology. This observation allows us to reinforce the validity of our results.

PR in BD: An Emerging Field of Research

We first observed that research on this topic and with this specific population is in its early stages. Our systematic review concerned all research works on this theme published before May 2021 and with no earlier cut-off date. Prior to 2010, in the field of BD research, the term "recovery" was only used in the literature to refer to "clinical recovery" or "functional recovery". Research interest in PR in BD has therefore lagged far behind that in the field of schizophrenia.

These observations are in contrast to the growing interest in PR in SMIs, shared by public authorities and mental health users. The COS published by Retzer et al. and selected in this review confirms this interest. A COS is a standardized collection of outcomes recommended to be reported in all controlled trials in a research area for community-based bipolar studies. This COS contained 11 outcomes including PR. PR is thus considered a central outcome for people with BD (18). Interventional research considering PR as a primary outcome in BD is still very limited: only five clinical studies, including two RCTs, were identified. However, five articles that were not selected for this current study presented study protocols on this subject (42–46).

PR in Relation to Clinical and Functional Recovery

The studies included in our review showed a significant negative correlation with current depression and anxiety, but not with mania. These results are consistent with those of the meta-analysis by Van Eck et al. (1) in schizophrenia, which showed a small to medium association between clinical and personal recovery. Depression would alter the feeling of PR, whereas PR could reduce symptoms and their thymic impact Best, 2020 (47). Among the subdomains of clinical recovery, affective symptoms were the most correlated with PR, and particularly depressive symptoms. Dubreucq et al. (48) longitudinally assessed the overlap and mutual distinctions between clinical and personal recovery, and found that clinical recovery and personal recovery, although distinct constructs, predict each other over time.

Van Eck et al. showed a positive but weak correlation between PR and functional recovery, while Dubreucq et al. put in evidence a mediating effect of quality of life, including various resources such as social support or autonomy. The studies included in our review focusing on BD, showed an important role for social factors, such as a valued role and the quality of social support.

Our results therefore confirm the reciprocal interplay of these different outcomes and the importance of taking them into account in care.

Specificities of PR in BD in Regard to Other SMIs

Some of the salient features of PR found here are similar to those described in other SMIs [for a review see (7)]: needing to find meaning in life and a fixed point in one's life despite fluctuations (14), taking responsibility for one's health and finding ways to self-manage one's disorders, making "the choice to get better" (12, 13), being employed and having a meaningful role (14, 20, 29, 39). In addition to other SMIs, but counterintuitively concerning mood disorders, PR does not seem to correlate very closely with the symptomatology itself, especially manic states (21, 22). The process seems to be more related to the relationship that people have with their thymic fluctuations than with the fluctuations themselves in a metacognitive way, including resilience (49).

Indeed, our findings provide additional knowledge on more specific elements of PR in BD: first, a new relationship with fluctuating mood states, which includes, on the one hand, an acceptance of this reality and, on the other hand, a decrease in hypervigilance and active struggle against these fluctuations, which may even include risk taking (12, 14, 22, 29, 39). This notion of acceptance had been found by Jagfeld's team in a review of qualitative studies on PR in BD (6). Acceptance concerned a form of ambivalence toward manic symptoms requiring a form of mourning, as well as acceptance of the repeated experience of losses (job, relationships) in connection with extreme mood states. Risk-taking includes inappropriate but potentially pleasurable activities, such as recreational drug use, binge drinking, and casual sex. It has been suggested that low-risk activities that are not associated with high levels of symptoms can be positive experiences and linked to better PR through experimenting and socializing more (39).

Moreover, our review highlights the fact that openness to others, including trust and closeness, seems to be a particularly important element of PR in BD (12, 14, 26). With regard to people with schizophrenia, Jose et al.'s 2015 review about PR in schizophrenia (50) found five themes of personal recovery specific to this disease: the process itself (non-linear, ongoing), self-orientation (e.g., understanding and accepting oneself, returning to a normal state), family relationships, social inclusion and connections, and recovery from illness (no symptoms, good functioning). The recent review by Leendertse (51) showed a strong correlation with the dimensions of hope, empowerment and meaning in life in PR and a lesser correlation with connectedness and identity. It would therefore seem that the notion of connectedness, linked to that of openness to others, is a PR lever that is rather specific to people living with BD compared to those living with schizophrenia. This result suggests that people suffering from BD are less concerned about the autistic symptoms and the social withdrawal present in the negative symptomatology of schizophrenia. Their need for quality social links would therefore be greater to improve their PR.

The CHIME Model and PR in BD

The CHIME conceptual framework is currently the most widely used framework for describing the PR process (5). However, the data in Leamy's review mainly concerned schizophrenia. The CHIME framework has been criticized for not being sensitive to the specific characteristics of certain populations, especially people with mood disorders, and for omitting the public relations themes of coping and courage or risk taking (for a review, see van Weeghel et al., 2019). While Todd's work in 2012 (13) found dimensions close to those of the CHIME framework, other studies identified new components of PR in this population.

These new elements are of two types. First, the CHIME framework describes elements of PR but does not address the underlying psychological processes. The latter appears to be central in the mechanism of PR in BD, based on the studies in our review. Indeed, the modalities of mental relationships with mood fluctuations have been considered important levers of PR (12). Concordantly, it has been shown (29) that certain regulatory mechanisms of manic or hypomanic states, such as dampening, impede PR. Other authors are exploring cognitive models that may provide explanations for the PR process in cognitive ways. In particular, it seems that a lack of control over fluctuations, acceptance or even a high level of risk-taking may promote PR (39).

Furthermore, the notion of relationships with others is only slightly developed in the CHIME model. However, our results suggest the importance of relationships and quality connections to others (12). Indeed, personal meaning in relationships may be more important in BD recovery than in other SMIs.

Our findings are quite consistent with those of the qualitative literature review conducted by Jagfeld et al. (6). These authors emphasized vocational goals and self-management skills and emphasized the question of relationships with others. Indeed, importance was given to the need to address the tensions in particularly intimate relationships caused by mental health difficulties and to deal with the risk of stigmatization associated with openness. Jagfeld et al. added a "tension" dimension to the CHIME framework, which links the latter subdomain to the issue of the need for acceptance of vulnerability and personal limitations, as well as the need to handle ambivalence about mania. The authors thus proposed a POETIC (Purpose and meaning, Optimism and hope, Empowerment, Tensions, Identity, Connectedness) framework that is supposed to be more specific to PR in BD, according to qualitative data (6).

Limitations

Our search strategy included three bibliographic databases, which may have limited the number of articles selected. As a result, it is possible that some data of interest could not be collected. We excluded all articles that were not specifically focused on people with BD. In this way, we were able to collect very specific information in a very complex area of research. This choice may also have limited the number of articles selected.

The literature search was limited to peer-reviewed studies available in English or French, which may not represent all the evidence and may have introduced a language bias.

The characteristics of PR in people with BD are in the early stages of exploration. The small number of articles to date may limit the scope of the evidence. Moreover, our work found that there is a lack of RCTs and works with a high level of scientific evidence. It is clear that future work will need to add to current scientific knowledge on the PR process in BD.

Future Directions and Clinical Implications

Our review has highlighted several possible avenues for future work.

The first avenue concerns the measurement tools of PR in BD. To date, the only scale specifically validated for the context of BD is the BRQ (8), which is the only tool that has been used in clinical research in specific bipolar populations. Our work highlighted that some new components of PR emerged from subsequent qualitative and observational studies. These elements could be taken into account in the construction of other measurement tools complementary to the BRQ.

The second avenue concerns the care tools and "recovery-oriented intervention" in BD. Our findings showed that a number of characteristics of health services supporting resilience, respect, hope and self-directed empowerment supported PR (19).

In 2017, Murray et al. proposed the use of mindfulness tools, such as mindfulness-based cognitive therapy (MBCT) programs or acceptance and commitment therapy (ACT) therapies. These tools would promote acceptance and decrease self-stigma (41). This proposal is consistent with our results; we can indeed hypothesize that these care tools are active in the cognitive relationships maintained with mood swings.

These principles are embodied not only in psychosocial interventions (41) but also in other fields, such as involvement in decision making regarding medication and constrained care. These issues are highly complex and require awareness and vigilance so that the development of self-management does not lead to a decrease in carers' commitment. In contrast, it is a question of finding and developing other, more humanistic, support methods that are a source of recovery. The results of the clinical trials collected in our review were consistent with these data. Recovery-focused care tools were already described (30, 31): they focused on self-determined goals and avoided stigmatizing discourses. This type of care helps people with BD understand and accept their disorders and develop self-care and a sense of agency. We did not find any clinical studies investigating the effects of pharmacological treatments with RA as the primary outcome.

Beyond the care tools themselves, it is also necessary to study communication modalities and the caregiving posture, as well as the partnership with peers in recovery-focused care, that could specifically facilitate PR. In the qualitative study conducted by Tse et al. in 2019 (17), the interviewed patients emphasized the value of learning from peers. Additionally, notions of empathic communication and hope instillation were mentioned. We can link this observation of Tse et al. to the previous results concerning the particular weight of connectedness and openness to others in the PR of people living with BD. Enabling people with BD to develop quality communication skills could be a central goal of care. The goal of recovery-focused care could first be embodied in the caregiving posture itself, through working with peers and valuing experiential knowledge. Additionally, the strengthening of the skills of openness to others, connectedness and bonding with others could be the focus of new care programs, as well as new research perspectives.

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

The protocol was designed by MC-E, MB, and LM. The reference screening was performed by MC-E undertaken by MD and BS. Data extraction was performed by MC-E and double-checked by MB and LM. The manuscript was written by MC-E, MB, and LM and reviewed for intellectual content by J-BH and BS. All authors contributed to the article and approved the submitted version.

REFERENCES

1. Van Eck RM, Burger TJ, Vellinga A, Schirmbeck F, de Haan L. The Relationship Between Clinical and Personal Recovery in Patients With Schizophrenia Spectrum Disorders: A Systematic Review and Meta-analysis. *Schizophr Bull*. (2018). 44:631018) doi: 10.1093/schbul/sbx088
2. Deegan P. Recovery: The lived experience of rehabilitation. (1988). doi: 10.1037/h0099565
3. Mead S, Copeland ME. What recovery means to us: consumersn. The Relations*Community Ment Health J*. (2000) 36:315 Hea doi: 10.1023/A:1001917516869
4. Anthony WA. Recovery from mental illness: The guiding vision of the mental health service system in the (1990s). *Psychosoc Rehabil J*. (1993) 16:11abil doi: 10.1037/h0095655
5. Leamy M, Bird V, Le Boutillier C, Williams J, Slade M. Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *Br J Psychiatry J Ment Sci*. (2011) 199:445 J M doi: 10.1192/bjp.bp.110.083733
6. Jagfeld G, Lobban F, Marshall P, Jones SH. Personal recovery in bipolar disorder: Systematic review and tal health: systematic review and narrative synthesis. orders: A Systematic Review and *J Affect Disord*. (2021) 292:375.n F doi: 10.1016/j.jad.2021.05.051
7. van Weeghel J, van Zelst C, Boertien D, Hasson-Ohayon I. Conceptualizations, assessments, and implications of personal recovery in mental illness: A scoping review of systematic reviews and meta-analyses. *Psychiatr Rehabil J*. (2019) 42:169bil doi: 10.1037/prj0000356
8. Jones S, Mulligan LD, Higginson S, Dunn G, Morrison AP. The bipolar recovery questionnaire: psychometric properties of a quantitative measure of recovery experiences in bipolar disorder. *J Affect Disord*. (2013) 147:34d.n doi: 10.1016/j.jad.2012.10.003
9. Shamseer L, Moher D, Clarke M, Ghersi D, Liberati A, Petticrew M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. *BMJ*. (2015) 350:g7647. doi: 10.1136/bmj.g7647
10. France, Haute autorité de santé. Niveau de preuve et gradation des recommandations de bonne pratique: état des lieux. (2016).
11. Sackett DL, Rosenberg WM. On the need for evidence-based medicine. *J Public Health Med*. (1995) 17:330h M
12. Mansell W, Powell S, Pedley R, Thomas N, Jones SA. The process of recovery from bipolar I disorder: a qualitative analysis of personal accounts in relation to an integrative cognitive model. *Br J Clin Psychol*. (2010) 49:193) n P doi: 10.1348/014466509X451447
13. Todd NJ, Jones SH, Lobban FA. 'Recovery' in bipolar disorder: how can service users be supported through a self-management intervention? A qualitative focus group study. *J Ment Health Abingdon Engl*. (2012) 21:114Abin doi: 10.3109/09638237.2011.621471
14. Veseth M, Binder PE, Borg M, Davidson L. Toward caring for oneself in a life of intense ups and downs: a reflexive-collaborative exploration of recovery in bipolar disorder. *Qual Health Res*. (2012) 22:119s. P doi: 10.1177/1049732311411487
15. Maassen EF, Regeer BJ, Regeer EJ, Bunders JFG, Kupka RW. The challenges of living with bipolar disorder: a qualitative study of the implications for health care and research. *Int J Bipolar Disord*. (2018) 6:23. doi: 10.1186/s40345-018-0131-y
16. Crowe M, Inder M. Staying well with bipolar disorder: a qualitative analysis of five-year follow-up interviews with young people. *J Psychiatr Ment Health Nurs*. (2018) 25:236nt H doi: 10.1111/jpm.12455
17. Tse S, Yuen WWY, Murray G, Davidson L, Lai Q, Kan A. Combining technical and expert-by-experience knowledge in the quest for personal recovery from bipolar disorder: a qualitative study. *BMC Psychiatry*. (2019) 19:368. doi: 10.1186/s12888-019-2357-3
18. Retzer A, Sayers R, Pinfold V, Gibson J, Keeley T, Taylor G, et al. Development of a core outcome set for use in community-based bipolar trials-A qualitative study and modified Delphi. *PLoS ONE*. (2020) 15:e0240518. doi: 10.1371/journal.pone.0240518
19. Tse S, Murray G, Chung KF, Davidson L, Ng KL Yu CH. Exploring the recovery concept in bipolar disorder: a decision tree analysis of psychosocial correlates of recovery stages. *Bipolar Disord*. (2014) 16:366., C doi: 10.1111/bdi.12153
20. Tse S, Davidson L, Chung K fai, Ng KL, Yu CH. Differences and Similarities Between Functional and Personal Recovery in an Asian Population: A Cluster Analytic Approach. Psychiatry Interpers Biol Process. (2014). 77:41:014 doi: 10.1521/psyc.2014.77.1.41
21. Grover S, Hazari N, Aneja J, Chakrabarti S, Sharma S, Avasthi A. Recovery and its correlates among patients with bipolar disorder: a study

from a tertiary care centre in North India. *Int J Soc Psychiatry.* (2016) 62:726hiat doi: 10.1177/0020764016676214

22. Dodd AL, Mezes B, Lobban F, Jones SH. Psychological mechanisms and the ups and downs of personal recovery in bipolar disorder. *Br J Clin Psychol.* (2017) 56:310hol. doi: 10.1111/bjc.12140
23. Echezarraga A, Las Hayas C, González-Pinto AM, Jones S. The Resilience Questionnaire for Bipolar Disorder: Development and validation. *Arch Psychiatr Nurs*. (2017). 31(4):376-85.
24. Kraiss JT, Ten Klooster PM, Chrispijn M, Stevens AWMM, Kupka RW, Bohlmeijer ET. Measuring personal recovery in people with bipolar disorder and exploring its relationship with well-being and social role participation. *Clin Psychol Psychother.* (2019) 26:540–9. doi: 10.1002/cpp.2371
25. Kraiss JT, Ten Klooster PM, Chrispijn M, Stevens AWMM, Kupka RW, Bohlmeijer ET. Psychometric properties and utility of the Responses to Positive Affect questionnaire (RPA) in a sample of people with bipolar disorder. *J Clin Psychol.* (2019) 75:1850Kloo doi: 10.1002/jclp.22819
26. Dunne L, Perich T, Meade T. The relationship between social support and personal recovery in bipolar disorder. *Psychiatr Rehabil J.* (2019) 42:100bil doi: 10.1037/prj0000319
27. Mezes B, Lobban F, Costain D, Longson D, Jones SH. Psychological factors in personal and clinical recovery in bipolar disorder. *J Affect Disord*. (2021). 280(Pt A):326-37.
28. Wynter E, Meade T, Perich T. Parental and partner role functioning and personal recovery in bipolar disorder. *J Clin Psychol*. (2021) 77:1985–96. doi: 10.1002/jclp.23127
29. Kraiss JT, Ten Klooster PM, Frye E, Kupka RW, Bohlmeijer ET. Exploring factors associated with personal recovery in bipolar disorder. *Psychol Psychother*. (2021) 94:667–85. doi: 10.1111/papt.12339
30. Todd NJ, Jones SH, Hart A, Lobban FA, A. web-based self-management intervention for Bipolar Disorder ng the impact of eight savoring and dampening strategies. recovery*J Affect Disord.* (2014) 169:21d.H doi: 10.1016/j.jad.2014.07.027
31. Jones SH, Smith G, Mulligan LD, Lobban F, Law H, Dunn G, et al. Recovery-focused cognitiverogramme for bipolar disorder in mental health services in Ireland: Results and learnings f*Br J Psychiatry.* (2015) 206:58y.G, doi: 10.1192/bjp.bp.113.141259
32. Jones SH, Akers N, Eaton J, Tyler E, Gatherer A, Brabban A, et al. Improving access to psychological therapies (IAPT) for people with bipolar disorder: summary of outcomes from the IAPT demonstration site. *Behav Res Ther.* (2018) 111:27. N, doi: 10.1016/j.brat.2018.09.006
33. Richardson T, White L. The impact of a CBT-based bipolar disorder psychoeducation group on views about diagnosis, perceived recovery, self-esteem and stigma. *Cogn Behav Ther.* (2019) 12. doi: 10.1017/S1754470X19000308
34. Enrique A, Duffy D, Lawler K, Richards D, Jones S. An internet-delivered self-management programme for bipolar disorder in mental health services in Ireland: Results and learnings from a feasibility trial. *Clin Psychol Psychother*. (2020) 27:925–39. doi: 10.1002/cpp.2480
35. Bauer, M. S., Crits-Christoph, P., Ball, W. A., Dewees, E., McAllister, T., Alahi, P. et al. (1991). Independent assessment of manic and depressive symptoms by self-rating. Scale characteristics and implications for the study of mania. Archives of General Psychiatry, 48(9), 807-812. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/1929771
36. Law H, Neil ST, Dunn G, Morrison AP. Psychometric properties of the questionnaire about the process of recovery (QPR). *Schizophr Res.* (2014) 156:184 Du doi: 10.1016/j.schres.2014.04.011
37. Corrigan PW, Salzer M, Ralph RO, Sangster Y, Keck L. Examining the factor structure of the recovery assessment scale. *Schizophr Bull.* (2004) 30:1035lzer doi: 10.1093/oxfordjournals.schbul.a007118
38. Lloyd C, King R, Moore L. Subjective and Objective Indicators of Recovery in Severe Mental Illness: a Cross-Sectional Study. *Int J Soc Psychiatry*. (2010). 56:220010 doi: 10.1177/0020764009105703
39. Mezes B, Lobban F, Costain D, Longson D, Jones SH. Psychological factors in personal and clinical recovery in bipolar disorder. *J Affect Disord.* (2020) 280:326–37. doi: 10.1016/j.jad.2020.11.044
40. Quoidbach J, Berry EV, Hansenne M, Mikolajczak M. Positive emotion regulation and well-being: Comparing the impact of eight savoring and dampening strategies. *Personal Individ Differ*. (2010) 49:368010) doi: 10.1016/j.paid.2010.03.048
41. Murray G, Leitan ND, Thomas N, Michalak EE, Johnson SL, Jones S, et al. Towards recovery-oriented psychosocial interventions for bipolar disorder: quality of life outcomes, stage-sensitive treatments, and mindfulness mechanisms. *Clin Psychol Rev.* (2017) 52:148ev.N doi: 10.1016/j.cpr.2017.01.002
42. Chan SHW, Tse S, Chung KF Yu CH, Chung RCK, Lo HHM. The effect of a brief mindfulness-based intervention on personal recovery in people with bipolar disorder: a randomized controlled trial (study protocol). *BMC Psychiatry.* (2019) 19:255. doi: 10.1186/s12888-019-2242-0
43. Faurholt-Jepsen M, Vinberg M, Frost M, Christensen EM, Bardram J, Kessing LV. Daily electronic monitoring of subjective and objective measures of illness activity in bipolar disorder using smartphones–the MONARCA II trial protocol: a randomized controlled single-blind parallel-group trial. *BMC Psychiatry.* (2014) 14:309. doi: 10.1186/s12888-014-0309-5
44. Kraiss JT, Ten Klooster PM, Chrispijn M, Trompetter HR, Stevens AWMM, Neuter E, et al. B-positive: A Randomized Controlled Trial of a Multicomponent Positive Psychology Intervention for Euthymic Patients With Bipolar Disorder - Study Protocol and Intervention Development [Internet]. Vol. 18, BMC psychiatry. *BMC Psychiatry*. (2018) 18:335. doi: 10.1186/s12888-018-1916-3
45. Lobban F, Dodd AL, Dagnan D, Diggle PJ, Griffiths M, Hollingsworth B, et al. Feasibility and acceptability of web-based enhanced relapse prevention for bipolar disorder (ERPonline): trial protocol. *Contemp Clin Trials.* (2015) 41:100ria doi: 10.1016/j.cct.2015.01.004
46. Tyler E, Lobban F, Sutton C, Depp C, Johnson S, Laidlaw K, et al. Feasibility randomised controlled trial of Recovery-focused Cognitive Behavioural Therapy for Older Adults with bipolar disorder (RfCBT-OA): study protocol. *BMJ Open.* (2016) 6:e010590. doi: 10.1136/bmjopen-2015-010590
47. Best MW, Law H, Pyle M, Morrison AP. Relationships between psychiatric symptoms, functioning and personal recovery in psychosis. *Schizophr Res.* (2020) 223:112 Py doi: 10.1016/j.schres.2020.06.026
48. Dubreucq J, Gabayet F, Godin O, Andre M, Aouizerate B, Capdevielle D, et al. Overlap and Mutual Distinctions Between Clinical Recovery and Personal Recovery in People With Schizophrenia in a One-Year Study. *Schizophr Bull.* (2022) 48:382022) doi: 10.1093/schbul/sbab114
49. Echezarraga A, Las Hayas C, Gonz114re M, Aouizerate B, Capdevielle D, et al. Overlap and Mutual Distinctions Between Clinical Recovery *Arch Psychiatr Nurs*. (2017) 31:376017) doi: 10.1016/j.apnu.2017.04.010
50. Jose D. Ramachandra null, Lalitha K, Gandhi S, Desai G, Nagarajaiah null. Consumer perspectives on the concept of recovery in schizophrenia: A systematic review Asian. *J Psychiatry.* (2015) 14:13.ec doi: 10.1016/j.ajp.2015.01.006
51. Leendertse JCP, Wierdsma AI, van den Berg D, Ruissen AM, Slade M, Castelein S, et al. Personal recovery in people with a psychotic disorder: a systematic review and meta-analysis of associated factors. *Front Psychiatry.* (2021) 12:622628. doi: 10.3389/fpsyt.2021.622628

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Social support and quality of life among chronically homeless patients with schizophrenia

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This study aimed to describe the sociodemographic characteristics, social support received, and quality of life of chronically homeless patients with schizophrenia in China. A self-prepared sociodemographic questionnaire, the Social Support Rating Scale (SSRS), European Five-dimensional Health Scale (EQ-5D), and Eysenck Personality were administrated to 3,967 chronically homeless and 3,724 non-homeless patients from the Department of Xiangtan Fifth People's Hospital, Hunan, China, between April 2011 and October 2016. Results indicated that the homeless patients were more likely to live outside the city and be ethnic minorities compared with non-homeless patients. Although the married proportion was higher among homeless patients, they had a higher rate of being divorced or widowed. Notably, the homeless patients had higher employment rates before illness, despite significantly lower education ($P < 0.001$). Chronically homeless patients with schizophrenia showed a lower score in the SSRS (30.29 ± 7.34 vs. 26.16 ± 10.04, $p < 0.001$); they had significantly lower objective support, subject support, social support, and EQ-Visual Analog Scale, Eysenck Personality Questionnaire-Psychoticism, and Eysenck Personality-Neuroticism scores ($p < 0.001$). Homeless patients may be worse off, and could be assisted by providing accommodation, family intervention, medical services (such as pain medication), and other comprehensive measures.

KEYWORDS

schizophrenia, homeless, non-homeless, quality of life, socio-support

Introduction

Despite rapid economic and social development and the progress of human civilization, the living condition of homeless patients with mental disorders is a growing concern. Homelessness is a social problem in China and remains understudied (1). A large number of homeless patients with schizophrenia is now challenging for mental health care management. The major contributing factors to homelessness are domestic violence, psychiatric disorder, housing crisis, and substance misuse (2–5). A recent systematic review and meta-analysis estimated the pooled prevalence of psychotic disorders among homeless people and found a remarkably high prevalence of schizophrenia (10.29% [95%, CI: 6.44, 16.02]), which was higher in developing than developed countries (22.15 vs. 8.83%) (6).

Social factors are important considering the status of homeless patients with schizophrenia and require urgent attention and action (7–9). Social and psychosocial interventions have been proven to be effective treatments and helpful in managing long-term psychiatric disorders (10). While psychiatry has shifted its focus to a more biological approach (11, 12), social factors are important regarding psychiatric disorders relating to social deprivation, rehabilitation, and enabling social inclusion. The degree to which society is willing to accept people with mental health problems impacts their quality of life (QoL). A 10-year Chinses cohort study evaluated predictors of homelessness in patients with schizophrenia during the follow-up period. Several social-related predictors were found: poor living conditions, low income, and little support from family (13). Most studies on this topic were conducted in developed countries (7, 14, 15), no associations between social support and QoL among homeless patients with schizophrenia were reported in China.

Our study aimed to describe the sociodemographic characteristics, social support, and QoL of homeless patients with schizophrenia compared to non-homeless patients, and provide some evidence to help the government establish interventions and social support systems.

Methods

The participants of this study were inpatients with schizophrenia from Xiangtan Fifth People's Hospital, Hunan Province. Located in the south-central area of China, Xiangtan Fifth People's Hospital is the largest specialty psychiatric hospital in the locality, with 1,200 hospital beds. The study protocol was approved by the Ethics Committees of the Fifth People's Hospital of Xiangtan (No. 20160217). All methods were performed in accordance with the relevant guidelines and regulations. Before being interviewed, written consent was obtained from all the participants and their guardians, and declarations of anonymity and confidentiality were made. Any modification was submitted to the ethics committee for discussion and approval.

Enrollment criteria

All participants in our study met the criteria of the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV) for a diagnosis of schizophrenia, were aged between 15 and 60 years, were in remission after treatment, and were able to understand and complete the questionnaire. The inclusion for the chronically homeless patients with schizophrenia were those who met the DSM- IV criteria and lived without suitable or temporary accommodation according to the European Typology of Homelessness and Housing Exclusion (ETHOS) definition, such as rooflessness, houselessness, living in insecure housing, living in inadequate housing (16); being homeless for more than 1 year or ≥four separate times in the last 3 years and four combined occasions equal to at least 1 year[1] The non-homeless patients with schizophrenia were those who met the DSM-IV criteria and had a fixed residence, usually sent to hospital by his family or himself.

Relief treatment process for the homeless patients

Almost all patients were found by concerned locals who called the hotline 1-1-0 so the homeless may be sent to the hospital by the police or by the Rescue Shelter (the department providing help for homeless people). When homeless patients were brought to the hospital, the Police or Rescue Shelter staff filled in the rescue application form, which included the time, place, mental and physical state, and personal belongings of the homeless when they were found. They received professional treatment after entering the hospital, and doctors carefully recorded changes in the patients' conditions. Some of the survey data came from these records. After the patient's remission, and upon obtaining clear identification information, the Rescue Shelter staff return the homeless patient to their registered household. A significant number of the participants could not state their personal, family, or any identification details because of their disorders; however, most of this information was recalled after treatment and from interaction with their relatives.

Self-prepared sociodemographic questionnaire

A self-prepared sociodemographic questionnaire was used, which covered nine dimensions: sex, ethnic group, age, and registered household [in China, Hukou usually refers to the place where they primarily lived, where the residents' parents registered their household when they were born (17)], educational levels, marriage, and employment.

Social support rating scale (SSRS)

The SSRS was revised by Xiao Shuiyuan and has good reliability and validity for the assessment of the physical and mental health of Chinese people (18, 19). It includes 10 items

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[1] Available from: https://www.hudexchange.info/resource/4847/hearth-defining-chronically-homeless-final-rule/

comprising objective support (three items), subjective support (four items), and utilization of socio-support (three items). The scoring method uses 1–4 points for each item numbered 1–5 and 8–10, 1 point for each item numbered 6–7, and 0 points for no response. A total score of ≥20 shows a high degree of social support; the higher the score, the higher the social support. A total score of less than 20 indicates less social support. Those who score between 20 and 30 have a general degree of social support, and those who score between 30 and 40 have a satisfactory degree of social support.

European quality of life five-dimensional scale

The EQ-5D contains simple content and shows high reliability and validity (20, 21). It is divided into two parts: the EQ-5D health description system and EQ-VAS, which can be used to evaluate health decline caused by certain diseases in patients. The EQ-5D health description system includes five dimensions: "mobility (walking about)," "looking after myself," "doing usual activities (e.g., going to school, hobbies, sports, playing, doing things with family or friends)," "having pain or discomfort," and "feeling worried, sad, or unhappy." Each dimension contains three levels: no problems, some problems, and a lot of problems. To better analyze health utility in our study, we used the time trade-off method utility value conversion table to convert the five dimensions of the EQ-5D health description system into integral values. As there is no corresponding conversion table in China, the EQ-5D health index score (between −0.11 and 1.00), obtained by the Japanese integration conversion table recommended in the literature was used in this study. The healthy index score = 1 constant term was used as the standard coefficient corresponding to the different levels of each dimension, in which the constant term = 0.152; the higher the score, the better the QoL. The EQ-VAS is a 20-cm vertical visual scale, with a top score of 100 representing "the best imaginable health" and a bottom score of 0 representing "the worst imaginable health." In this study, the actual corresponding score divided by 100 was used, that is, the EQ-VAS health score was between 0 and 1.

Eysenck personality questionnaire

The EPQ measures traits of four personality dimensions: psychoticism (P), extroversion (E), neuroticism (N), and lie scale (L) (22).

All evaluations were conducted by specially trained psychiatrists. Uniform instructions and appropriate explanations were given for sentences that were incomprehensible to the participants, but without providing further hints. The test lasted for at least 30 min for each participant. The homeless in remission and the non-homeless completed self-prepared sociodemographic questionnaire, the SSRS, EQ-5D, and EPQ questionnaires based on the enrollment criteria. Since most of the participants' relatives were found, the veracity of the questionnaire answers was further checked.

Statistical analysis

All the data in this study were processed and analyzed used SPSS version 25.0. Data were examined for the presence of missing values, influential values and outliers, skewness, and kurtosis. Scales and indices were tested for reliability. Kolmogorov–Smirnov one-sample test was used to measure the normal distribution of continuous variables. Categorical variables were tested by Chi-square test, and continuous variables were tested by Mann-Whitney U test in this study. Correlation between different scales were analyzed by Spearman correlation. Further regression models (stepwise) were then carried out in the participants' samples. EQ-VAS were the dependent variable, and the independent factors were sex, age, objective support, subjective support, social support, P, E, N and L. A two-tailed p value < 0.05 was considered significant in this study.

Results

Demographics and clinical characteristics

This study was conducted between April 2011 and October 2016. All the homeless patients during this period were primarily screened. A total of 4,983 homeless patients were included. Among them, 379 (7.8%) refused to participate, 334 (6.7%) did not meet the inclusion criteria, and 293 (5.9%) had incomplete data. Finally, data of 3,967 patients were included. We also included non-homeless patients with schizophrenia in similar numbers for comparison. 4,500 patients during this period were screened, 520 (11.6%) refused to participate, 127 (2.8%) did not meet the inclusion criteria, and 119 (2.6%) had incomplete data. Thus, data of 3,734 non-homeless patients were included.

The participants were mainly of Han ethnicity, accounting for 89–95.2% of the total population. The proportion of ethnic minorities among the homeless patients was higher than that among the non-homeless (11.0 vs. 4.8%, $P < 0.001$). The homeless patients were often found outside the city (87.0%) and most were migrants (58.1%), while non-homeless patients were often sent to the hospital from the place where they primarily lived (70.3%), and were mostly local residents (86.3%). Most patients were not married, with an unmarried rate of over 56.6%. Homeless patients had a higher rate of being divorced and widowed (17.7%) compared with non-homeless patients (13.7%). The employment rate of homeless patients before falling ill was higher than that of non-homeless patients (72.6 vs. 52.4%, $P < 0.001$). A large proportion of them had a low

TABLE 1 Comparison of sociodemographic differences between the homeless and non-homeless schizophrenia patients.

Sociodemographic differences	Homeless ($n = 3{,}967$)	Non-homeless ($n = 3{,}734$)	χ^2	P
Sex			0.189	0.664
Male	2,565(64.7%)	2,432(65.1%)		
Female	1,402(35.3%)	1,302(34.9%)		
Age	36.11 ± 10.04	33.34 ± 11.72	11.147	0.001
Rural	3,450(87.0%)	2,624(70.3%)	321.706	0.001
HAN ethnicity	3,531(89.0%)	3,554(95.2%)	99.506	0.001
Smoking				
Smokers	1,876(47.3%)	1,856(49.7%)	4.493	0.034
Non-smokers	2,091(52.7%)	1,878(50.3%)		
Household registration			1630.739	0.001
Xiangtan	1,664(41.9%)	3,222(86.3%)		
Non-Xiangtan	2,303(58.1%)	5,12(13.7%)		
Education level			1147.656	0.001
Primary school or below	3,501(88.3%)	2,000(53.6%)		
Junior high school	2,94(7.4%)	893(23.9%)		
High school	172(4.3%)	841(22.5%)		
Senior high school or above	172(4.3%)	841(22.5%)		
Employment (Employed-before illness)			373.576	0.001
Stable job	768(19.4%)	576(15.4%)		
Temporary job	2,112(53.2%)	1,334(36.0%)		
Jobless	1,087(27.4%)	1,814(48.6%)		
Marital status			96.258	0.001
Single	2,245(56.6%)	2,518(67.4%)		
Married or remarried	1,018(25.7%)	704(18.9%)		
Divorced or widowed	704(17.7%)	512(13.7%)		

educational level (88.3% primary school education level or below among homeless patients compared with 53.6% among the non-homeless). Almost half of the participants were smokers (47.3–49.7%). The mean age of the homeless patients was 36.11 years, which was higher than the non-homeless, who had a mean age of 33.34 years. There was no significant difference in sex between the groups ($P = 0.664$) (Table 1).

Comparisons of socio-support, QoL, and personality between the homeless and non-homeless patients

Homeless patients with schizophrenia had significantly lower total scores on the Social Support Rating Scale (SSRS; 30.29 ± 7.34 vs. 26.16 ± 10.04, $p < 0.001$), with significantly lower objective, subjective, and social support ($p < 0.001$). The European Quality of Life Five-Dimensional Scale (EQ-5D) health index scores among homeless patients were significantly lower, although the EQ Visual Analog Scale (EQ-VAS) score was higher (Table 2). Homeless patients with schizophrenia had significantly higher scores on the Eysenck Personality Questionnaire for psychoticism (EPQ-P; 55.84 ± 9.97 vs. 52.99 ± 8.90, $p < 0.001$) and neuroticism (EPQ-N; 55 ± 11.14 vs. 49.18 ± 11.58, $p = 0.001$).

Spearman correlation analysis was performed to evaluate the relationships between homeless status and SSRS, EQ-5D, EQ-VAS, and EPQ scores. We found that homeless status was negatively associated with SSRS, EQ-VAS, EPQ-E, and EPQ-L scores but positively associated with EPQ-P and EQP-N scores, whereas it showed no significant relationship with EQ-5D health description (Table 3).

The correlations between the factors measured by the SSRS, EQ-5D, EQ-VAS, and EPQ were examined. SSRS total scores had a positive correlation with objective ($r = 0.736$, $p < 0.01$), subjective ($r = 0.672$, $p < 0.01$), and social support ($r = 0.526$, $p < 0.01$). SSRS total scores were also significantly related to EQ-5D health description ($r = 0.092$, $p < 0.01$) and EQ-VAS ($r = 0.210$, $p < 0.01$) but not as strongly as with EPQ-E (extroversion) ($r = 0.342$, $p = 0.008 < 0.01$). This indicated a significant positive linear fit of the SSRS and EPQ but only a slightly positive linear fit of the SSRS and EQ-5D. In contrast, the SSRS had negative relationships with EPQ-P and EPQ-N ($r = -0.279$, $p < 0.01$, and $r = -0.224$, $p < 0.01$, respectively) (Table 3).

TABLE 2 Comparison of SSRS, EQ-5D, and EPQ differences between the homeless and non-homeless schizophrenia patients.

Variables	The non-homeless	The homeless	Z	p
EQ-5D Health description	0.74 ± 0.11	0.73 ± 0.12	−1.12	0.262
EQ-VAS	11.21 ± 0.18	14.59 ± 0.23	−12.719	<0.001
SSRS total scores	30.29 ± 7.34	26.16 ± 10.04	−25.64	<0.001
objective support	15.54 ± 3.98	15.08 ± 5.12	−3.49	<0.001
subjective support	6.98 ± 3.12	4.86 ± 4.31	−36.13	<0.001
use of social support	7.52 ± 2.04	6.48 ± 2.49	−18.93	<0.001
EPQ-P	52.99 ± 8.90	55.84 ± 9.97	−14.17	<0.001
EPQ-E	49.62 ± 9.65	46.75 ± 11.73	−11.27	<0.001
EPQ-N	49.18 ± 11.58	55 ± 11.14	−22.11	<0.001
EPQ-L	52.62 ± 8.45	52.11 ± 8.85	−2.59	<0.001

After controlling for confounding factors, the following variables were still significant for lower QoL (which was evaluated by EQ-VAS): being homeless (Beta $= -0.156$, $t = -14.29$, $p < 0.001$), female (Beta $= -0.2$, $t = -19.406$, $p < 0.001$), higher EPQ-E score (Beta $= -0.047$, $t = -3.941$, $p < 0.001$), higher EPQ-N score (Beta $= -0.119$, $t = -10.195$, $p < 0.001$), and higher EPQ-L score (Beta $= -0.156$, $t = -13.756$, $p < 0.001$). Older age (Beta $= 0.219$, $t = 20.112$, $p < 0.001$), more objective support (Beta $= 0.283$, $t = 18.419$, $p < 0.001$), more subjective support (Beta $= 0.077$, $t = 5.171$, $p < 0.001$), more subjective support (Beta $= 0.124$, $t = 8.493$, $p < 0.001$), and higher EPQ-P score (Beta $= 0.183$, $t = 16.891$, $p < 0.001$) were associated with higher QoL (Table 4).

Discussion

Our study systematically compared the sociodemographic characteristics, social support, and QoL between homeless and non-homeless patients with schizophrenia. To the best of our knowledge, this is the first study of its kind in China. The results showed that homeless patients were less likely to obtain social support. Although no difference in the EQ-5D health index was observed between the two groups, homeless patients experienced more general anxiety, depression, and physical pain as evaluated by the EQ-VAS.

The results indicated considerable sociodemographic differences between homeless and non-homeless patients. Most patients included were of Han ethnicity, accounting for 89–95.2% of the participants. The proportion of ethnic minorities among homeless patients was higher than that among non-homeless. This could be because, by the end of 2016, 99.5% of the local residents were of Han ethnicity, while 0.5% were ethnic minorities. Furthermore, the homeless patients were more likely to live primarily outside the city (87%), which is different to the findings on homeless patients with schizophrenia in other countries (23). This result may be related to the fact that Xiangtan is a major agricultural city, and a large section of the population lives in the countryside. And we recorded their primary hometown in the Hukou system, which were different from the methods in studies from other countries.

Our study found that most patients included were not married, with an unmarried rate of over 56.6%. The homeless patients had a higher rate of being divorced or widowed (13.7 vs. 17.7%). Regardless of cultural norms and socio-economic contexts, marriage can provide important benefits to persons with schizophrenia through stronger social networks and support and a better QoL (24). However, cross-cultural comparative research has documented lower rates of marriage and higher rates of separation and divorce among persons with schizophrenia when compared to the general population (25). First, patients with schizophrenia encounter barriers to forming matrimonial alliances because the most opportune time for courtship and marriage often corresponds with an early, insidious onset of the illness (26). Second, among those who were married, the poorer prognosis of the illness and lower socio-economic status were shown to be predictors of divorce and separation (27). In this study, although only a small proportion of homeless patients had stable jobs, the previous employment rate of homeless patients (72.6%) was much higher than that of the non-homeless (52.4%). The lack of social acceptance of patients with schizophrenia could be one of the main obstacles to marriage or employment.

The average age of homeless patients was higher compared with previously reported literatures on homeless people. This may due to the earlier onset of schizophrenia and a relatively lower education level in our sample (5, 8, 28). Patients with schizophrenia may be supported by their relatives during the early stages of the disease, but as the condition worsens, their families experience heavy economic burden, slowly eroding treatment confidence, and leading to abandonment (29). The results also showed that almost half of the patients were smokers (47.3–49.7%) (30), which was markedly higher than the general

TABLE 3 The spearman correlation between the homeless, SSRS, EQ-5D, EQ-VAS, and EPQ.

Variables	The homeless	SSRS total scores	Objective support	Subjective support	Use of social support	EQ-5D Health description	EQ-VAS	EPQ-P	EPQ-E	EPQ-N
The homeless	1									
SSRS total scores	−0.244**	1								
Objective support	−0.034**	0.736**	1							
Subjective support	−0.352**	0.672**	0.442**	1						
Use of social support	−0.187**	0.526**	0.429**	0.563**	1					
EQ-5D Health description	−0.011	0.092**	0.071**	0.095**	0.028**	1				
EQ-VAS	−0.122**	0.210**	0.157**	0.196**	0.178**	0.446**	1			
EPQ-P	0.134**	−0.279**	−0.224**	−0.267**	−0.279**	0.185**	−0.006	1		
EPQ-E	−0.106**	0.342**	0.322**	0.219**	0.187**	0.023**	0.074**	−0.066**	1	
EPQ-N	0.209**	−0.224**	−0.150**	−0.225**	−0.090**	−0.198**	−0.088**	0.086**	−0.161**	1
EPQ-L	−0.027**	0.177**	0.103**	0.199**	0.209**	0.011	−0.089**	−0.048**	0.103**	−0.220**

** presents $p < 0.01$.

population (20%) (31), but lower than in the report by Torchalla et al. (80.8%) (32).

The homeless patients were less likely to receive social support. There is also a need to provide supported accommodation for people whose social skills are limited by severe psychiatric and intellectual disabilities, such as through required skill training and psychosocial and vocational training (23, 33). The Chinese government has tried to provide more social security for those with mental illness by building a prevention and treatment network, releasing favorable health care and medical insurance policies, providing financial aids for their guardians, establishing their rights and obligations, and granting tax reductions for enterprises hiring them. The Mental Health Law of the People's Republic of China (34) was issued on May 1st, 2013, which provides measures for the administration of relief for the homeless and beggars living in the city, along with various local supporting laws and regulations to ensure their implementation.

The QoL of patients with schizophrenia is affected by many factors, such as housing, healthcare, basic human rights, vocational skills training, and other domains (33, 35). Housing is crucial for improving one's QoL (35). Our study found that in patients with schizophrenia, the QoL of non-homeless patients may be better than that of homeless patients. An important difference is relatively stable housing. Our study also found that the QoL of patients with schizophrenia was generally low; the highest EQ-5D health index was 0.848, and the median was 0.768. They commonly felt worried, sad, or unhappy (50.7%), and experienced pain or discomfort (54.8%). Fond et al. (36) also reported that more than half of the patients (51.5%) reported moderate to extreme physical pain, while only 2.7% were administered analgesic drugs; physical pain is highly frequent and undertreated in homeless participants with mental illness. Attention should also be paid to ex-homeless women; a recent study reported that ex-homeless women with schizophrenia were more exposed to verbal, physical, and sexual violence, which may strongly affect their mental and physical health as well as QoL and increase their suicide risk (37). Our results also indicated that homeless patients with schizophrenia tended to have more abnormal levels of psychoticism and neuroticism than non-homeless patients, which indicate higher levels of antisocial behavior and emotional distress, respectively. However, they had lower scores in the dimensions of extroversion and dissimulation. Lower scores on the Lie scale indicate reduced concern with socially desirable behavior. These results may indicate that the homeless are more poorly adjusted psychologically than the non-homeless. There is existing literature that has found that high neuroticism and psychoticism and low extroversion are associated with poorer life outcomes (38–40).

There are several limitations to this study. First, we examined a sample of inpatients, rather than a general sample of outpatients or the homeless. Second, hospital

TABLE 4 Multivariate analysis for variables associated with EQ-VAS.

	Unstandardized coefficients		Standardized coefficients		
Variables	***B***	**SE**	**Beta**	***t***	**Sig.**
Being homeless	−4.149	0.29	−0.156	−14.29	<0.001
Sex (Female)	−5.559	0.286	−0.2	−19.406	<0.001
Age	0.265	0.013	0.219	20.112	<0.001
SSRS					
Objective support	0.816	0.044	0.283	18.419	<0.001
Subjective support	0.261	0.05	0.077	5.171	<0.001
Social support	0.708	0.083	0.124	8.493	<0.001
Eysenck Personality Questionnaire					
Psychoticism	0.254	0.015	0.183	16.891	<0.001
Extroversion	−0.058	0.015	−0.047	−3.941	<0.001
Neuroticism	−0.135	0.013	−0.119	−10.195	<0.001
Lie	−0.239	0.017	−0.156	−13.756	<0.001

costs and length of stay were not included in the study. Previous studies demonstrated that homeless patients were hospitalized longer and had excess costs (41, 42). Third, some important factors were not considered, such as material dependence, intellectual disability, and other mental health problems. Material dependence is an important factor among homeless individuals with mental illness as reported by developed countries (43, 44). Finally, the population was predominantly from the city of Xiangtan in the Hunan Province and the results may not be generalized to other populations.

Homeless patients with schizophrenia were less likely to have social support, and there is a need for more supported accommodation and skills training for patients limited by severe psychiatric diseases. The patients' QoL was relatively low; they experienced general anxiety, depression, and physical pain. This indicates that more attention must be given to the emotional state of patients while providing active assistance, and better medical treatment must be provided to reduce their physical pain appropriately, and to improve their QoL.

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 Ethic Committees of the Fifth People's Hospital of Xiangtan. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

Author contributions

JindC and JH: conceptualization, methodology, and supervision. JH: formal analysis and writing the original draft. JinlC: data collection. ZT and YS: data analysis. HS and SL: help in data collection and validation.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Qiu D, Zufferey C. *Homelessness in China, Faces of Homelessness in the Asia Pacific*. London: Routledge (2017). 28–46 p. doi: 10.4324/9781315475257-3

2. Fowler PJ, Toro PA, Miles BW. Pathways to and from homelessness and associated psychosocial outcomes among adolescents leaving the foster care system. *Am J Public Health.* (2009) 99:1453–8. doi: 10.2105/AJPH.2008.142547

3. Beijer U, Scheffel Birath C, DeMartinis V, Af Klinteberg B. Facets of male violence against women with substance abuse problems: women with a residence and homeless women. *J Interpers Violence.* (2018) 33:1391–411. doi: 10.1177/0886260515618211

4. Alison Duke RN, Searby A. Mental ill health in homeless women: a review. *Issues Ment Health Nurs.* (2019) 40:605–12. doi: 10.1080/01612840.2019.1565875

5. Folsom D, Jeste DV. Schizophrenia in homeless persons: a systematic review of the literature. *Acta Psychiatr Scand.* (2002) 105:404–13. doi: 10.1034/j.1600-0447.2002.02209.x

6. Ayano G, Tesfaw G, Shumet SJB. The prevalence of schizophrenia and other psychotic disorders among homeless people: a systematic review and meta-analysis. *BMC Psychiatry*. (2019) 19:1–14. doi: 10.1186/s12888-019-2361-7

7. Lam JA, Rosenheck R. Social support and service use among homeless persons with serious mental illness. *Int J Soc Psychiatry*. (1999) 45:13–28. doi: 10.1177/002076409904500103

8. Foster A, Gable J, Buckley J. Homelessness in schizophrenia. *Psychiatr Clin North Am*. (2012) 35:717–34. doi: 10.1016/j.psc.2012.06.010

9. Allen J, Balfour R, Bell R, Marmot M. Social determinants of mental health. *Int Rev Psychiatry*. (2014) 26:392–407. doi: 10.3109/09540261.2014.928270

10. Brooke-Sumner C, Petersen I, Asher L, Mall S, Egbe CO, Lund C. Systematic review of feasibility and acceptability of psychosocial interventions for schizophrenia in low and middle income countries. *BMC Psychiatry*. (2015) 15:1–12. doi: 10.1186/s12888-015-0400-6

11. Frangou S. Resilience embodied: a paradigm shift for biological research in psychiatry. *Biol Psychiatr: Cogn Neurosci Neuroimag.* (2021) 6:139–40. doi: 10.1016/j.bpsc.2020.11.009

12. Kapur S, Phillips AG, Insel TR. Why has it taken so long for biological psychiatry to develop clinical tests and what to do about it? *Mol Psychiatr.* (2012) 17:1174–9. doi: 10.1038/mp.2012.105

13. Ran M, Chan C, Chen E, Xiang M, Caine E, Conwell Y. Homelessness among patients with schizophrenia in rural China: a 10-year cohort study. *Acta Psychiatr Scand.* (2006) 114:118–23. doi: 10.1111/j.1600-0447.2006.00746.x

14. Durbin A, Nisenbaum R, Kopp B, O'Campo P, Hwang SW, Stergiopoulos V. Are resilience and perceived stress related to social support and housing stability among homeless adults with mental illness? *Health Soc Care Commun.* (2019) 27:1053–62. doi: 10.1111/hsc.12722

15. Gabrielian S, Young AS, Greenberg JM, Bromley E. Social support and housing transitions among homeless adults with serious mental illness and substance use disorders. *Psychiatr Rehabil J.* (2018) 41:208. doi: 10.1037/prj0000213

16. Edgar B. The ETHOS definition and classification of homelessness and housing exclusion. *Eur J Homelessness.* (2012) 6:219–25.

17. Chan KW, Buckingham W. Is China abolishing the hukou system? *China Q.* (2008) 195:582–606. doi: 10.1017/S0305741008000787

18. Xiao SJCMHJ. Social support rating scale. *Chin Ment Health J.* (1993) 13:42–46. doi: 10.1080/03124079308410665

19. Sarason IG, Levine HM, Basham RB, Sarason BR. Assessing social support: the social support questionnaire. *J Person Soc Psychol.* (1983) 44:127–39. doi: 10.1037/0022-3514.44.1.127

20. Wang H, Kindig DA, Mullahy J. Variation in Chinese population health related quality of life: results from a EuroQol study in Beijing, China. *Q Life Res.* (2005) 14:119–32. doi: 10.1007/s11136-004-0612-6

21. Rabin R, Charro F. EQ-SD: a measure of health status from the EuroQol Group. *Ann Med.* (2001) 33:337–43. doi: 10.3109/07853890109002087

22. Qian M, Wu G, Zhu R, Zhang S. Development of the revised Eysenck personality questionnaire short scale for Chinese (EPQ-RSC). *Acta Psychol Sin.* (2000) 32:317.

23. Gowda GS, Gopika G, Manjunatha N, Kumar CN, Yadav R, Srinivas D, et al. Sociodemographic and clinical profiles of homeless mentally ill admitted in mental health institute of South India: 'Know the Unknown' project. *Int J Soc Psychiatry.* (2017) 63:525–31. doi: 10.1177/0020764017714494

24. Salokangas RK, Honkonen T, Stengard E, Koivisto AM. To be or not to be married—that is the question of quality of life in men with schizophrenia. *Soc Psychiatry Psychiatr Epidemiol.* (2001) 36:381–90. doi: 10.1007/s001270170028

25. Thara R, Srinivasan TN. Outcome of marriage in schizophrenia. *Soc Psychiatry Psychiatr Epidemiol.* (1997) 32:416–20. doi: 10.1007/BF00788182

26. Isaac M, Chand P, Murthy P. Schizophrenia outcome measures in the wider international community. *Br J Psychiatry Suppl.* (2007) 50:s71–7. doi: 10.1192/bjp.191.50.s71

27. L.F. Saugstad. Social class, marriage, and fertility in schizophrenia. *Schizophr Bull.* (1989) 15:9–43. doi: 10.1093/schbul/15.1.9

28. Romaszko J, Cymes I, Dragańska E, Kuchta R, Glińska-Lewczuk K. Mortality among the homeless: causes and meteorological relationships. *PLoS ONE.* (2017) 12:e0189938. doi: 10.1371/journal.pone.0189938

29. Ran MS, Yang LH, Liu YJ, Huang D, Mao WJ, Lin FR, et al. The family economic status and outcome of people with schizophrenia in Xinjin, Chengdu, China: 14-year follow-up study. *Int J Soc Psychiatry.* (2017) 63:203–11. doi: 10.1177/0020764017692840

30. Castle D, Baker AL, Bonevski B. Editorial: Smoking and schizophrenia. *Front Psychiatry.* (2019) 10:738. doi: 10.3389/fpsyt.2019.00738

31. Reitsma MB, Kendrick PJ, Ababneh E, Abbafati C, Abbasi-Kangevari M, Abdoli A, et al. Spatial, temporal, and demographic patterns in prevalence of smoking tobacco use and attributable disease burden in 204 countries and territories, 1990–2019: a systematic analysis from the Global Burden of Disease Study 2019. *Lancet.* (2021) 397:2337–60. doi: 10.1016/S0140-6736(21)01169-7

32. Torchalla I, Strehlau V, Okoli CT, Li K, Schuetz C, Krausz M. Smoking and predictors of nicotine dependence in a homeless population. *Nicotine Tob Res.* (2011) 13:934–42. doi: 10.1093/ntr/ntr101

33. Nielssen OB, Stone W, Jones NM, Challis S, Nielssen A, Elliott G, et al. Characteristics of people attending psychiatric clinics in inner Sydney homeless hostels. *Med J Aust.* (2018) 208:169–73. doi: 10.5694/mja17.00858

34. Chen H, Phillips M, Cheng H, Chen Q, Chen X, Fralick D, et al. Mental Health Law of the People's Republic of China (English translation with annotations): translated and annotated version of China's new Mental Health Law. *Shanghai Arch Psychiatry.* (2012) 24:305–21. doi: 10.3969/j.issn.1002-0829.2012.06.001

35. Luhrmann TM. "The street will drive you crazy": why homeless psychotic women in the institutional circuit in the United States often say no to offers of help. *Am J Psychiatry.* (2008) 165:15–20. doi: 10.1176/appi.ajp.2007.07071166

36. Fond G, Tinland A, Boucekine M, Girard V, Loubiere S, Boyer L, et al. The need to improve detection and treatment of physical pain

of homeless people with schizophrenia and bipolar disorders. Results from the French Housing First Study. *Prog Neuropsychopharmacol Biol Psychiatry*. (2019) 88:175–80. doi: 10.1016/j.pnpbp.2018.07.021

37. Tinland A, Boyer L, Loubiere S, Greacen T, Girard V, Boucekine M, et al. Victimization and posttraumatic stress disorder in homeless women with mental illness are associated with depression, suicide, and quality of life. *Neuropsychiatr Dis Treat*. (2018) 14:2269–79. doi: 10.2147/NDT.S161377

38. Dubayova T, Nagyova I, Havlikova E, Rosenberger J, Gdovinova Z, Middel B, et al. Neuroticism and extraversion in association with quality of life in patients with Parkinson's disease. *Q Life Res*. (2009) 18:33–42. doi: 10.1007/s11136-008-9410-x

39. Ridgewell C, Blackford JU, McHugo M, Heckers S. Personality traits predicting quality of life and overall functioning in schizophrenia. *Schizophr Res*. (2017) 182:19–23. doi: 10.1016/j.schres.2016.10.007

40. van Dijk FA, Schirmbeck F, Haan L. A longitudinal analysis of the effects of neuroticism and extraversion on subjective well-being in patients with schizophrenia. *Psychiatry Res*. (2018) 259:538–44. doi: 10.1016/j.psychres.2017.11.011

41. Hwang SW, Weaver J, Aubry T, Hoch J. Hospital costs and length of stay among homeless patients admitted to medical, surgical, and psychiatric services. *Med Care*. (2011) 350–54. doi: 10.1097/MLR.0b013e318206c50d

42. Choi KR, Castillo EG, Seamans MJ, Grotts JH, Rab S, Kalofonos I, et al. Mental health conservatorship among homeless people with serious mental illness. *Pscyhiatr Serv*. (2021) 73:appi.ps.202100254. doi: 10.1176/appi.ps.202100254

43. Opalach C, Romaszko J, Jaracz M, Kuchta R, Borkowska A, Buciński A. Coping styles and alcohol dependence among homeless people. *PLoS ONE*. (2016) 11:e0162381. doi: 10.1371/journal.pone.0162381

44. Fazel S, Khosla V, Doll H, Geddes J. The prevalence of mental disorders among the homeless in western countries: systematic review and meta-regression analysis. *PLoS Med*. (2008) 5:e225. doi: 10.1371/journal.pmed.0050225

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A gamified augmented reality vocational training program for adults with intellectual and developmental disabilities: A pilot study on acceptability and effectiveness

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Objectives: The Augmented Reality Games to Enhance Vocational Ability of Patients (REAP) was an augmented reality vocational training program that provided skills training in the context of a psychiatric rehabilitation program. It was implemented over 10 weeks and consisted of gamified augmented reality café training scenarios and bridging group activities to facilitate transfer of learning to the work context. This pilot study aimed to explore the acceptability and effectiveness of the REAP program when carried out with adults with intellectual and developmental disabilities attending work therapy. Its objectives were: (1) to obtain feedback from participants and trainers on their experiences and acceptability of the REAP program and (2) to measure changes in vocational and cognitive skills of participants in the REAP program.

Materials and methods: This was a pretest–posttest mixed methods study. 15 adults with intellectual and developmental disabilities attending work therapy in a non-profit organization participated in the REAP program and their vocational trainers were involved in assisting in this program. Feasibility Evaluation Checklist (FEC) and the Neurobehavioral Cognitive Status Exam (Cognistat) were administered at baseline, post-training and eight weeks after training. The participants and their trainers also provided user feedback *via* semi-structured interviews.

Results: Majority of the participants and trainers found the REAP program to be useful and interesting. They also found that the augmented reality games were user-friendly and provided a unique opportunity to acquire new skills. Participants who engaged in this program showed a significant improvement in vocational skills and aspects of cognitive skills, which were maintained eight weeks after training.

Conclusion: The gamified augmented reality vocational training was feasible and accepted by both adults with intellectual and developmental disabilities and their trainers. When integrated with bridging sessions to facilitate transfer of learning to existing work therapy, participants on the REAP program showed significant improvements in vocational skills and aspects of cognitive skills. Future experimental studies with larger sample size could provide stronger evidence on its effectiveness in improving vocational outcomes.

KEYWORDS

augmented reality, vocational training, transfer of learning, cues and prompts, intellectual and developmental disabilities, Neuropsychological and Educational Approach to Remediation

Introduction

Adults with intellectual and developmental disabilities can lead meaningful and fulfilling lives, when interventions are in place to equip them with skills or adaptive strategies to maximize participation in daily living, leisure, community living and work. Technology and assistive devices have traditionally been used to improve functional outcomes through skills training or task adaptations. For example, a computer game was used to train decision-making skills in a group of adults with intellectual disabilities (1). Another study explored the use of vibrating watches as a time management tool to assist in task transition and completion (2). Recently, a mindfulness and relaxation game was designed to teach stress management strategies to persons with intellectual disabilities (3). Skills training using a carefully designed gamified platform has the ability to facilitate the learning of new tasks in a scaffolded and interesting manner, thus promoting internal motivation to engage in the learning process (4).

While computer-based skills training packages allow persons with intellectual and developmental disabilities to learn in a structured manner, recent advancements in augmented and virtual reality have enabled rehabilitation practitioners to provide a more immersive training environment. Virtual Reality (VR) transports the users to a fully immersive environment, which replicates aspects of reality and enables stimulation of the senses as well as interaction with objects in a simulated environment (5). On the other hand, Augmented Reality (AR) enables the users to perceive a more realistic training environment, as the real environment is superimposed on virtual three-dimensional graphics and images (6). Therefore, users will still be able to view the real environment while they interact with the virtual objects. As a result, AR has the added advantage of providing users with better control of their actions and balance, thus minimizing hazards such as colliding with walls (7).

Despite these beneficial features, the use of AR as a skills training platform for adults with intellectual and developmental disabilities has not been extensive. In an application of AR to adults with autism, a preliminary study considered the use of AR smartglasses as a social communication aid (8). Other studies explored the use of AR in daily living or community living skills training for adults with intellectual disabilities. One study used video models to teach the step of ironing, making bed and setting an alarm clock (9). These video models were activated by the rear-facing camera on iPads and appeared as an overlay across a target spot. Two studies used mobile applications that combined AR features with global positioning systems (GPS), to provide real-time navigation cues to participants (10, 11). One of the mobile applications could also function as a search engine for location-based information from the selected venue (11). Gamification using an AR application was also implemented to teach the use of an automated teller machine (ATM), where the AR mobile phone application provided cues over an ATM simulator presented on an iPad (12). Overall, these studies were small sample designs involving not more than five research participants.

In the functional area of work, attempts have been made to utilize AR to train various vocational skills, in order to enhance employability and vocational opportunities. One study used an AR platform to present video instructions on horticulture work for eight adults with intellectual disabilities (13). These contents were activated at selected GPS coordinates and displayed on tablets. Another team developed a marker-based mobile AR application named “Paint-cAR,” to support participants in a car maintenance vocational rehabilitation program who were learning how to repair car paints (14). Results of this cross-sectional evaluation study showed that participants felt the AR training boosted their confidence and satisfaction in picking up this vocational skill. Lastly, AR was also used as a vocational task prompting system

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Abbreviations: AR, Augmented Reality; REAP, Augmented Reality Games to Enhance Vocational Ability of Patients; NEAR, Neuropsychological and Educational Approach to Remediation.

called ARCoach, where three participants learning how to assemble food items were given AR-generated audio and visual cues whenever they made a mistake in the tasks (6).

Despite wanting to work, adults with intellectual and developmental disabilities often have difficulties obtaining and sustaining employment (15, 16). Services for adults with intellectual and developmental disabilities offer a variety of vocational rehabilitation programs, ranging from work skills training, sheltered employment, supported employment to hybrid models of employment (15, 17). In order to maximize their chances of attaining supported or open employment, skills training programs are often implemented to prepare them for a variety of jobs, in areas such as food and beverage, retail, housekeeping, etc. Simulating different job tasks of varying complexities in the natural environment can be challenging and time-consuming, which will limit the number of clients who can be trained within a specific period. In addition, it is assumed that repeated practice of essential steps of work tasks will result in eventual work competence. However, open employment often involves situations that require problem solving and responding to social cues, which may be difficult to enact in real-life training (18). Such situations may include knowing how to respond when a customer accidentally knocks over another customer's drinks, knowing what to do when the towel near the kitchen stove catches fire, etc. Gamification using AR may be a viable solution in providing a systematic and enjoyable way of training vocational skills, which allow simulation of problematic work scenarios without the need for huge training spaces. Therefore, there are possible benefits in using AR to maximize clients' potential for higher vocational attainment. However, as described earlier, research on the use of AR in vocational rehabilitation is still at the infancy stage. Hence, there is a need to investigate the acceptability, feasibility and effectiveness of using AR in improving vocational skills.

The Augmented Reality Games to Enhance Vocational Ability of Patients (REAP) was an AR-enabled vocational training program that provided adjunctive skills training in the context of an existing vocational rehabilitation program. A User-Centered Design approach was adopted in the AR prototype development, which emphasized on the clients' needs and goals to ensure meaningful gamification (19). Taking this into consideration, the program used the framework from the Neuropsychological and Educational Approach to Remediation (NEAR). NEAR is derived from neuropsychology, educational psychology, behavior learning theory and theory of self-determination (20). It is a cognitive rehabilitation framework and program that incorporates education psychology's emphasis on creating a learning environment that enhances motivation to learn. Therefore, features such as personalizing characters, contextualizing the games to simulate real work environment, provision of user choices, evoking interest through attractive multi-media images were incorporated into the gamified training scenarios in REAP. As important, the AR games were built to provide attributional and strategy feedback, so that trainers could guide clients to evaluate their task responses (21). The storyboard for each training scenario was developed based on the framework of Perceive, Recall, Plan and Perform system of task analysis, to break down the work tasks into steps to scaffold learning (22, 23). In addition to using the NEAR framework to guide motivational enhancements, the AR games used NEAR-style bridging activity groups to facilitate transfer of learning from the games to the existing vocational rehabilitation programs and other aspects of daily lives. Even though adults with intellectual and developmental disabilities have cognitive limitations, REAP attempted to harness the therapeutic components of rehearsal and strategy-building to facilitate vocational skills acquisition and functional gains.

The aim of this pilot study was to explore the acceptability and effectiveness of the REAP program. Its objectives were:

1. To obtain feedback from participants and trainers on their experiences and acceptability of the REAP program.
2. To measure changes in vocational and cognitive skills of participants in the REAP program.

Materials and methods

Study design

This was a pilot study to evaluate REAP's augmented reality (AR) gamified platform prototype and training sessions, to ascertain the feasibility, acceptability, safety, and effectiveness for adults with intellectual and developmental disabilities. A pretest–posttest mixed methods design was adopted, with follow-up after eight weeks. Quantitative data such as vocational skills and cognitive functions was collected at three time points. A user feedback interview was also conducted with the research participants and the trainers, yielding quantitative and qualitative data.

Participants and setting

The study was conducted in collaboration with Bizlink Center, a non-profit organization with the mission of assisting persons with disabilities in the provision of employment through vocational training and various employment programs. The pilot trial was conducted in Bizlink Headquarters, which provided work therapy in their workshops and social enterprises, as well as their Day Activity Center, which provided aspects of work training. Clients who met the following inclusion and exclusion criteria were recruited for this pilot study.

Inclusion criteria:

- Persons with intellectual or developmental disabilities who were receiving services at Bizlink.
- Able to converse in English and understand English instructions, as the AR games were in the English medium.
- Able to ambulate without any physical assistance.

Exclusion criteria:

- Unable to speak and understand English.
- Co-morbid epilepsy, which would affect gains from AR vocational training.

As the study was conducted during the COVID-19 pandemic period, open or supported employment were not the main goals for the majority of Bizlink's clients and their caregivers. Nevertheless, the center strived to maintain meaningful engagement of work tasks and vocational opportunities that matched the clients' interests and functional performance.

Besides the clients, user feedback interviews were also conducted with staff trainers at Bizlink, who were trained to assist in the implementation of REAP with the participants. This was done to examine their perceptions of the usefulness of REAP as an adjunctive skills training to the center's work therapy.

REAP: Gamified augmented reality vocational training

The principles of Neuropsychological and Educational Approach to Remediation (NEAR) were used to develop the REAP program, with its emphasis on personalization, contextualization and transfer of learning to daily activities (24). The AR gamified training scenarios were developed using Unity 3D (25) and implemented on a RhinoX AR headset from Ximmerse (18). A set of handheld controllers came with the headset.

Gamified augmented reality platform

Four training scenarios were developed to contextualize the vocational training within a virtual sandwich café, namely (1) work etiquette, (2) sandwich making, (3) serving drinks, and (4) cashiering (18). The storyboard for each training scenario was developed based on the framework of Perceive, Recall, Plan and Perform system of task analysis, to break down the work tasks into steps to scaffold learning (22, 23). Participants could also personalize the game by typing in their names and assuming the role of an employee in the café.

In the "Work Etiquette" scenario, participants had to remember their work schedules and pick out the appropriate dress code, thereby training their attendance, timeliness and grooming. The working days were randomized into seven different permutations to reduce practice bias, while the clothing selections were also placed on random buttons. The system would generate visual hints upon unsuccessful attempts, such as "Tuesday is not a working day." This enabled participants to acquire the ability to respond to verbal cues and prompts.

In the "Sandwich Making" scenario, participants were given a tutorial on building a sandwich, after which they had to fulfill customers' orders of different sandwich combinations. The participants would use the handheld controller to aim the laser pointer at the correct ingredient, then click and hold a button on the controller to pick up the item. A recipe book was available to provide information on the ingredients required for each sandwich, out of an array of 20 ingredients. Participants could flip-through the recipe book before it closed after 15 s of inactivity. Difficulty of this game increased with the increased number of ingredients and reduced visual cues on the ingredients required. For example, at levels one and two, participants were guided by a pointer to the right ingredients for the sandwiches. At level three, participants had to build sandwiches comprising three ingredients, but a message would pop up if they picked the wrong ingredients. At level four, the participants had to build sandwiches comprising up to five ingredients and there were no visual cues to alert them if they picked the wrong ingredients. Therefore, this scenario targeted workplace tolerance, instruction-taking, sustained attention and working memory. See **Figure 1** for a screenshot of this scenario.

In the "Serving Drinks" scenario, participants were required to pick up the correct drink from the refrigerator and place it on a serving tray. It involved in-hand manipulation of the handheld controller and some level of eye-hand coordination, as the participants were required to hold onto the controller's button as they moved the drink and placed it on the allocated spot on the tray (see **Figure 2**). This scenario targeted adherence to workplace safety rules and use of proper body mechanics.

Lastly, the "Cashiering" scenario required participants to perform a series of steps on monetary transactions with the customers (see **Figure 3**). Participants were first prompted to greet the customers based on the time of day, followed by keying in the customers' verbal orders into a point-of-sale machine. Upon receiving payment from customers, they would have to give the correct amount of change. Game difficulty was determined by the number of orders given by the customers and the number of times that the customers were asked to repeat the orders. For example, at level three, participants had to remember up to three order items (combinations of drinks and sandwiches) and they could click on the "repeat order" button up to three times to listen to the order again. At level

FIGURE 1
Sandwich making scenario.

four, participants had to remember up to five order items, which were also combinations of sandwiches and drinks. Besides working memory and money management skills, the scenario also targeted customer service.

During the development phase of the prototype, user testing was carried out with volunteers who consented and provided some preliminary feedback about the games, so that modifications could be made to enhance user acceptability. For more details of the AR gamified platform, please refer to Chiam et al. (18).

The AR system also collected data of the participants' game performance. Such data included the duration of each game session, number of attempts made in the training scenarios during each session, whether the participants passed or failed each attempt and number of hints requested by the participants in each session. At the higher levels, the sandwich training scenario also included a few multiple-choice questions to test participants' problem-solving and judgment in unexpected situations (for example, if an ingredient of a sandwich ran out). Number of errors of these multiple-choice questions per session was also captured.

REAP training protocol

During baseline assessments, participants were screened using the Neurobehavioral Cognitive Status Exam (Cognistat) (26) and the occupational therapists would then allocate different modules in the AR games according to participants' cognitive functioning and vocational goals. A training plan was drawn up, where participants would either move across different scenarios of the same difficulty level, or increase the difficulty levels of each scenario. The number of prompts and cues given would also be tailored to each participant's goals, functioning level and progress. In general, the participants were also allocated to "Beginner," "Intermediate," or "Advanced" level. At the "Beginner" level, participants could make use of the external cues within the gamified platform to complete each scenario. They could progress to the next difficulty level of each scenario when they accumulated ten correct attempts. At the "Intermediate" level, the participants were encouraged to utilize internal strategies as much as they could, instead of relying on external cues from the gamified platform. They could progress to the next difficulty level of each scenario when they accumulated ten correct attempts. At the "Advanced" level, the participants had to achieve ten consecutive correct attempts in each scenario without the use of external cues before they could progress to the next difficulty level. A set of remediation and compensatory strategies was also prepared, and the centers' trainers were trained to assist in implementing these strategies according to the agreed plans and goals.

Participants participated in the REAP program three times a week for 10 weeks. In each week, two sessions involved AR games and one session was a bridging group. Each session lasted for 30 min. During the AR game session, participants engaged in the AR games and were given a break after every 10 min or as and when needed. Such frequency and duration of intervention were similar to most cognitive remediation programs (27) and within the duration range of programs that utilized virtual/augmented reality for persons with intellectual disabilities (5, 28). The participants engaged in different training scenarios as recommended and their performance was recorded by the trainers. Participants moved up the levels or across different training scenarios once they made ten successful

FIGURE 2
Serving drinks scenario.

attempts. Depending on their set goals, participants would be required to make ten consecutive successful attempts or non-consecutive ones. The usage of in-game visual and/or auditory hints also varied in accordance with the participants' goals. In addition, cognitive strategies were taught during the games and reinforced during the bridging groups.

Bridging groups were designed to reinforce strategies learned during AR game sessions as well as to generalize the skills learned to real-life situations. These group sessions were facilitated by the research team, following an intervention manual. Through engagement in a variety of group games and activities, participants practiced their life skills and shared their AR game experiences with others. At the end of each bridging group, participants were reminded to use these cognitive strategies during their subsequent AR sessions.

Outcome measures

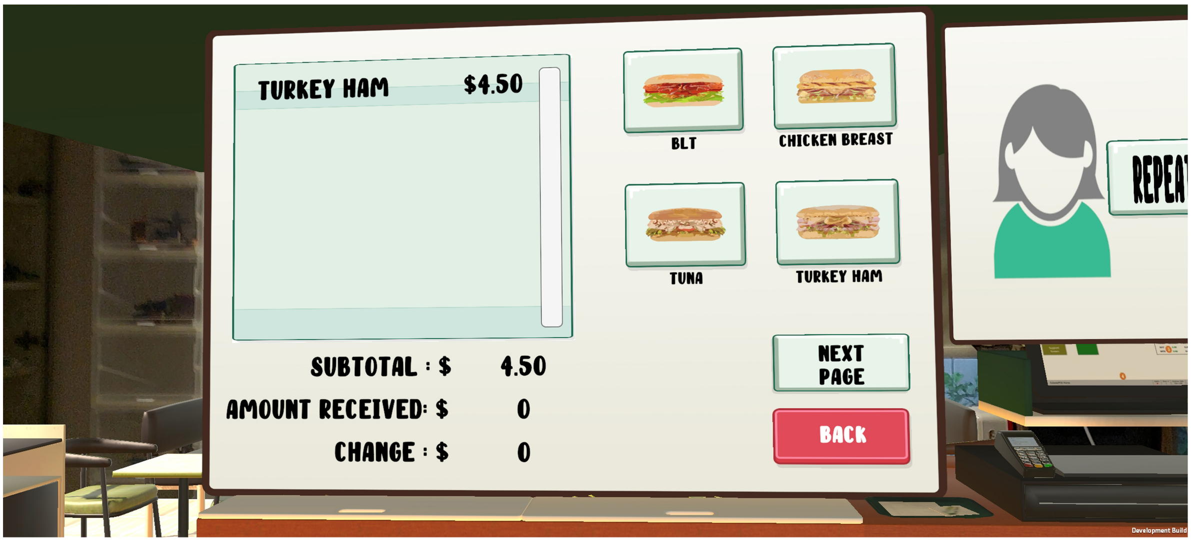
The following assessments were carried out:

Vocational skills assessment: Feasibility evaluation checklist

The Feasibility Evaluation Checklist (FEC) is an observer-rated tool on work skills and behaviors that are relevant for persons with cognitive or physical disabilities (29). It measures aspects of general productivity, safety in the workplace and interpersonal behavior (29, 30). The rater will evaluate the person's level of feasibility for competitive employment for each item, which is rated as "independent," "minimal assist," "moderate assist," "not evaluated," or "non-employable." A total score is then computed, with a higher score indicating better vocational skills (30). FEC was administered by the trainer who was in-charge of the specific participant for work therapy. It was completed at baseline, post-training and eight-weeks after completion of the training. The participant might have a different trainer for the AR sessions, depending on the training schedule.

Cognitive assessment: Neurobehavioral cognitive status exam

Cognistat is a cognitive screening instrument widely used with adults with cognitive impairment (31, 32). The cognitive domains measured are: orientation, attention, language (comprehension, repetition and naming), constructional ability, verbal memory, mental calculations, and reasoning (similarities and judgment). Each domain (except for memory and orientation) has a screening component. If the participant fails the screening component, the metric component will be administered. A higher score indicates a higher level of cognitive performance in each domain (32). This assessment was carried out as part of a larger study involving the use of REAP with persons with neurodevelopmental and psychiatric


TURKEY HAM $4.50

SUBTOTAL : $ 4.50
AMOUNT RECEIVED: $ 0
CHANGE : $ 0

FIGURE 3
Cashiering scenario.

disorders. Cognistat was administered at baseline, post-training and eight-weeks after completion of the training.

User feedback semi-structured interview

A semi-structured user feedback interview was also administered post-training with the participants, to obtain information on their experiences in participating in the REAP program. Questions were rephrased or simplified according to the level of understanding of the participants and the areas covered were:

1. The extent that participants found the REAP training program to be a useful component of their work therapy. Participants were asked to rate on a four-point Likert scale (1 = not useful at all to 4 = very useful). They were also asked for their opinions on the useful and non-useful aspects of the program.
2. Areas not covered in their standard work therapy that the REAP training program had addressed.
3. Participants' interest in the REAP training (AR games and bridging groups): participants were asked to rate from 1 = not interesting at all to 4 = very interesting.
4. Ease of use: participants were asked to rate on a four-point Likert scale on whether the games were easy to understand (1 = not easy at all to 4 = very easy) and how comfortable it was for them to use the AR headset and hand controllers (1 = not comfortable at all to 4 = very comfortable). They were also asked to elaborate on their experiences.
5. Duration of the REAP program: participants were asked to rate on a three-point Likert scale (1 = too short, 2 = just right, 3 = too long).
6. How safe they felt when engaging in the AR games.
7. Overall experience of the program.

In addition, the user feedback semi-structured interview was conducted with trainers who assisted in implementing REAP with the participants. Questions covered the following aspects:

1. Trainers' perception of the usefulness of REAP as an adjunct to the center's work therapy: they were asked to rate on a four-point Likert scale (1 = not useful at all to 4 = very useful). Trainers were also asked for their opinions on the useful and non-useful aspects of the program.
2. Areas not covered in standard work therapy that the REAP program could uniquely address.
3. Strategies that trainers had utilized during the REAP program, which were generalized to daily activities and work therapy.
4. Ease of teaching participants to play the AR games: trainers were asked to rate on a four-point Likert scale on the level of ease in teaching the participants to play the games (1 = not easy at all to 4 = very easy). They were also asked to share their experiences in teaching the participants.
5. Duration of the REAP program: trainers were asked to rate on a three-point Likert scale (1 = too short, 2 = just right, 3 = too long).
6. Observed interest level of the participants: trainers were asked to rate from 1 = not interesting at all to 4 = very interesting.
7. Any safety concerns.

8. Feasibility of implementing the REAP program across more sites: trainers were asked to rate from 1 = not feasible at all to 4 = feasible for all the sites.
9. Overall experience of the program.

Quantitative and qualitative data were obtained from these semi-structured interviews.

Study procedure

Recruitment was conducted at Bizlink Center's Headquarters and the Day Activity Center. Purposive sampling was done by the center managers and staff, based on the inclusion/exclusion criteria and clients' goal of engaging in work-related training. The study was explained to the clients and caregivers and consent was taken before commencement of the study. Ethics approval was obtained from the Singapore Institute of Technology Institutional Review Board (study number: 2020004). All participants and their caregivers consented to the participation of this study before REAP training was implemented.

Upon informed consent, the following procedures were implemented:

1. Baseline assessments: (within the two weeks before commencement of REAP training): Feasibility Evaluation Checklist (FEC) and Cognistat were administered. The Cognistat was administered by the research team with the participants, while FEC was administered by the trainers.
2. REAP training program: research team worked with the centers' trainers to conduct the AR games and bridging groups. Sessions were conducted three times a week for 10 weeks (30 sessions).
3. Post-training assessments (within the two weeks after completion of REAP training): FEC and Cognistat were administered. The research team also carried out the user feedback interviews with the participants and trainers.
4. Eight-week follow-up assessments: FEC and Cognistat were again administered to evaluate any change in vocational skills/behavior and cognitive functioning.

Data analyses

Quantitative statistical analyses were performed using IBM SPSS Statistics Version 28 (33). Descriptive statistical data was obtained from the participants' demographic profiles, user feedback interviews and game performance (duration per session, number of correct attempts, number of in-game hints, number of errors in the multiple-choice questions, etc.). Repeated Measures ANOVA was used to test for changes in vocational skills and cognitive functioning as measured by FEC and Cognistat, respectively. Repeated Measures ANOVA was also conducted to test for changes in game performance over the beginning, middle and final sessions. Statistical significance was set at $p \leq 0.05$.

The user feedback qualitative data was entered into Quirkos 2.4.2 (34) and thematic analysis was carried out. The data was labeled and coded by the first author and a codebook was created to describe each code. The first, third, and fourth authors looked through the codes to determine convergence and divergence through an iterative process, as well as to make comparisons between participants' and trainers' experiences (35).

Results

Participants' demographics

A total of 15 participants and 11 trainers took part in this pilot study. The participants' mean age was 31.47 years (SD = 12.07) and 53.30% of them were females. 11 participants had intellectual disabilities while four participants had autism spectrum disorder. All participants were unmarried at the point of study. Other demographic profiles are shown in **Table 1**.

Game performance

Based on initial cognitive screening, 13 participants were allocated to the Beginner game level and two were allocated to the Intermediate level. At the end of the 10-week program, ten participants remained at the Beginner level, one went up to the Intermediate level and four participants achieved the Advanced level (see **Table 1**). Participants who continued to require external cues from the gamified platform would stay in the Beginner level, while the participant who did not rely on external cues to get correct responses was at the Intermediate level. Finally, participants who were able to achieve ten consecutive correct attempts moved up to the Advanced level.

Repeated Measures ANOVA was conducted to test for changes in game performance over the beginning, middle and final sessions. As Mauchly's Test indicated that the assumption of sphericity had been violated for the measurements of "duration per session" and "number of attempts made per session," χ^2 (2) = 6.16–9.96, $p < 0.05$, degrees of freedom were corrected using Greenhouse-Geisser estimates of sphericity (ε = 0.65–0.73). Results showed that there were no significant time effects on these two measures. On the other hand, Mauchly's Test showed that the assumption of sphericity had been met for the other game performance measurements. With sphericity assumed, it was found that there were significant reduction in number of wrong attempts in the multiple-choice

TABLE 1 Participants' demographic profile and game level.

Profile and game level ($n = 15$)	***N* (%)**
Gender	
Female	8 (53.3%)
Male	7 (46.7%)
Setting	
Bizlink Headquarters	9 (60.0%)
Bizlink day activity center	6 (40.0%)
Comorbid psychiatric conditions	
None	10 (66.7%)
Depression	3 (20.00%)
Schizophrenia	1 (6.7%)
Attention-deficit hyperactivity disorder	1 (6.70%)
Years of receiving services at Bizlink center	
0–5 years	10 (66.7%)
6–10 years	4 (26.7%)
11 years and above	1 (6.7%)
Initial game level	
Beginner	13 (86.7%)
Intermediate	2 (13.3%)
Final game level achieved	
Beginner	10 (66.7%)
Intermediate	1 (6.7%)
Advanced	4 (26.7%)
Participants' profile ($n = 15$)	***Mean (SD)***
Age (in years)	31.47 (12.07)
Years of education	14.82 (1.93)

questions over the three time-points $F(2,28) = 4.52$, $p = 0.02$, $\eta p^2 = 0.24$. Table 2 shows the mean scores and the time effect of the game performance measurements over the three time points.

Vocational skills and cognitive skills

Repeated Measures ANOVA was also carried out to investigate changes in vocational and cognitive skills as measured by FEC and Cognistat, respectively. FEC and Cognistat scores were obtained at baseline, post-training and eight weeks after training. One participant became unwell just before Cognistat was due for administration at the eight-week follow-up period. As a result, full data could not be obtained from her and her Cognistat scores were not used for the data analysis.

Mauchly's Test indicated that the assumption of sphericity had been violated for the Cognistat domains of "orientation" and "similarity," χ^2 (2) = 7.63–12.39, $p < 0.05$. Therefore, degrees of freedom were corrected using Greenhouse-Geisser estimates of sphericity (ε = 0.61–0.68). Results showed that there were no significant time effects on these two cognitive domains. On the other hand, Mauchly's Test showed that the assumption of sphericity had been met for the measurements of FEC total scores, Cognistat total scores and all the other Cognistat domain scores. With sphericity assumed, it was found that there were significant improvements in FEC total scores, Cognistat memory domain, Cognistat reasoning (judgment) domain and Cognistat total scores over the three time-points $F(2,26–28)$ = 3.29–4.76, $p < 0.05$, ηp^2 = 0.20–0.27. Table 3 shows the mean scores and the time effect of the vocational and cognitive skills measurements over the three time points.

Participants and trainers' feedback-quantitative results

Figures 4–8 show the user ratings of participants and trainers on the usefulness, ease of use, interest, comfort level and duration of the REAP program. As seen from the figures, majority of the participants and trainers found the program to be slightly useful or very useful. While most of them found the AR games to be easy to understand and interesting, a small number of them had some difficulty with it. The participants also largely found the AR equipment to be quite comfortable or very comfortable to use. In terms of the duration of the REAP program, about 47% of the participants found the duration to be just right, with 20% finding it too short and 33% finding it too long. Conversely, 73% of the trainers found the duration to be just right, while 9% found the program to be too short and 18% found it to be too long.

Participants and trainers' feedback-qualitative results

Four themes were generated from the thematic analysis of the interviews with participants and trainers. They were: (1) benefits of games and technology; (2) skills training and strategy learning; (3) tailoring the program to meet individual needs and contexts; and (4) technical aspects of the augmented reality platform. Participants' quotes were labeled with "P," while trainers' quotes were labeled with "T."

Benefits of games and technology

Six trainers felt that the nature of augmented reality provided a unique experience for participants and staff to experience working in a food and beverage industry, while picking up a new technological skill. It was also deemed to be less costly because there was no need to set up a real café and virtual ingredients could be "reused." Nine participants indicated that the program enabled them to try out new things in a virtual world, which were different from their

TABLE 2 Repeated measures for mean scores on augmented reality game performance at beginning, middle, and final sessions.

Game measurement	Beginning session Mean (SD)	Middle session Mean (SD)	Final session Mean (SD)	Time effect			
				F	*df*	*p*	ηp^2
Duration per session (minutes)	27.13 (18.30)	26.87 (7.59)	24.60 (6.10)	0.21	1.30	0.72	0.02
Number of attempts per session	7.67 (4.88)	9.80 (7.06)	9.07 (7.26)	0.45	1.45	0.58	0.03
Number of correct attempts	6.13 (4.42)	8.40 (7.03)	7.88 (6.85)	21.07	2	0.56	0.04
Number of wrong attempts	1.53 (1.41)	1.40 (1.81)	1.33 (1.45)	0.68	2	0.93	0.01
Number of hints requested	0.80 (1.32)	3.00 (4.97)	2.73 (4.03)	1.94	2	0.16	0.12
Number of errors in multiple-choice questions	3.67 (4.25)	1.00 (2.65)	0.80 (1.70)	4.52	2	*0.02	0.24

*Significant at $p \leq 0.05$.

TABLE 3 Repeated measures for Feasibility Evaluation Checklist (FEC) total scores and Cognistat domain and total scores at baseline, post-training, and at eight-week follow-up.

Measurement	Baseline Mean (SD)	Post-intervention Mean (SD)	Eight-week Follow-up Mean (SD)	Time effect			
				F	*df*	*p*	ηp^2
Feasibility Evaluation Checklist (FEC) total	42.40 (11.53)	47.07 (12.82)	49.73 (16.34)	3.74	2	*0.04	0.21
Cognistat orientation	9.64 (3.54)	10.50 (2.68)	9.07 (3.08)	1.17	1.36	0.31	0.08
Cognistat attention	4.79 (2.64)	6.00 (2.96)	5.93 (2.34)	1.45	2	0.25	0.10
Cognistat comprehension	3.79 (1.63)	4.36 (1.15)	4.36 (1.69)	2.25	2	0.13	0.15
Cognistat repetition	6.64 (3.37)	7.43 (3.11)	7.86 (3.30)	0.90	1.80	0.41	0.07
Cognistat naming	5.71 (1.44)	5.71 (1.07)	6.00 (1.11)	1.07	2	0.36	0.08
Cognistat construction ability	3.71 (1.98)	3.57 (1.28)	3.36 (1.91)	0.38	2	0.69	0.03
Cognistat memory	3.57 (3.86)	7.36 (4.55)	7.50 (4.67)	10.21	2	*<0.001	0.44
Cognistat calculations	2.36 (2.06)	3.07 (1.44)	2.50 (1.35)	1.63	2	0.22	0.11
Cognistat Similarities	1.64 (2.53)	2.57 (3.18)	3.21 (3.47)	3.28	1.22	0.08	0.20
Cognistat judgment	0.86 (1.51)	1.43 (1.34)	2.14 (1.99)	4.76	2	*0.02	0.27
Cognistat total	42.71 (17.18)	52.00 (14.79)	51.50 (18.49)	4.53	2	*0.02	0.26

*Significant at $p \leq 0.05$.

standard vocational rehabilitation. They could experiment with behaviors associated with tasks such as taking customers' orders and cashiering in a self-paced and less anxiety provoking manner:

> *"Can learn things in a different way... and how to manage situation that is happening and how to break things into parts. Eg what is most important, what is less important, what is not important. Those that are not important can slowly take my time to figure out" (P16).*

This was echoed by trainers, who stated that many of their clients might not get a chance to interact with customers or do cashiering and they could "*learn better when they could try things out through game*" (T04).

Five participants and two trainers also highlighted that the program was fun and engaging. Some of them found it to be an interesting and relaxing way to learn and became more motivated:

> *"Fun, exciting for clients, it is a good bonding time for clients and trainers. It can increase sense of confidence for some clients and allow them to learn new things" (T05).*

One trainer also pointed out that the use of augmented reality platform minimized direct physical contact with

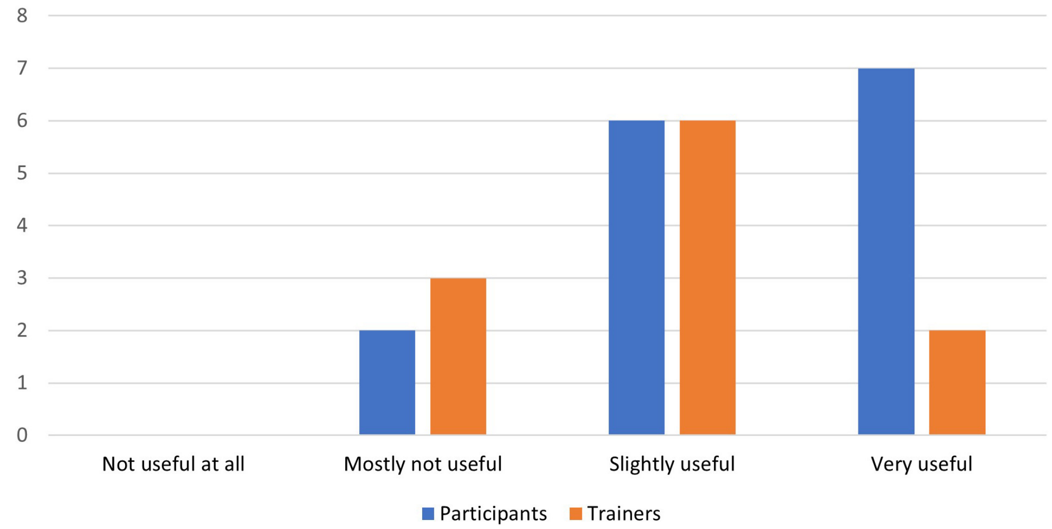


FIGURE 4
Feedback on usefulness of the Augmented Reality Games to Enhance Vocational Ability of Patients (REAP) program.

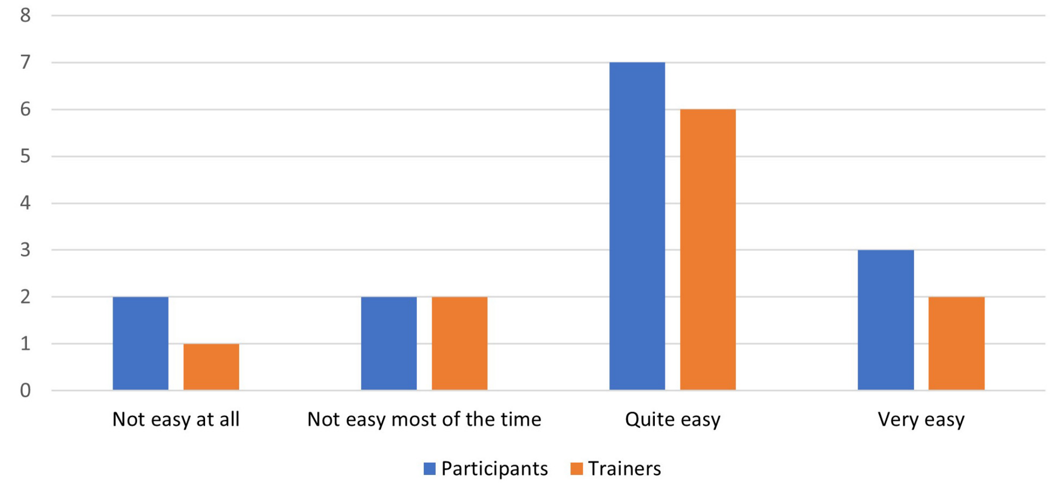


FIGURE 5
Feedback on the ease of use of the Augmented Reality Games to Enhance Vocational Ability of Patients (REAP) augmented reality games.

participants during COVID-19 pandemic period, which helped in the execution of training.

Skills training and strategy learning

Seven participants and four trainers felt that the program trained aspects of cognitive functions, such as attention, memory and problem-solving. Memory recall was specifically identified by participants as an area that they benefited in. When asked about cognitive strategies used during the games, the trainers identified breaking down the tasks, verbalizing the ingredients aloud, using visual aids and giving verbal prompts as the commonly used ones.

Majority of the trainers also felt that the program taught new skills such as work etiquette, customer service, reading and use of technology. Conversely, only three participants stated that they picked up new skills during the process, which were mainly soft skills and self-regulation skills:

> *"Learn how to be patient when you start to be stressed out and it's difficult to calm down and be patient. I'm a person who gets angry easily, Have to tell myself to calm down and do things step by step in front of me" (P16).*

Participants and trainers also feedback that the psychomotor skills required in the "Serving Drinks" scenario were too

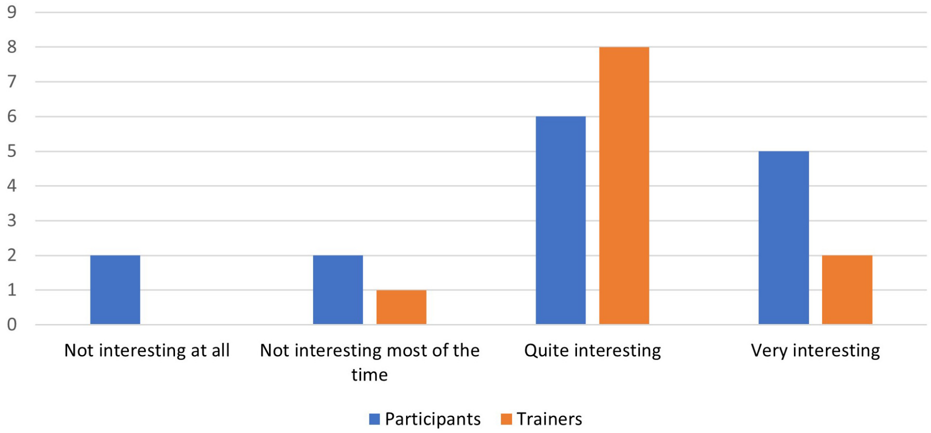


FIGURE 6
Feedback on the interest level of the Augmented Reality Games to Enhance Vocational Ability of Patients (REAP) program.

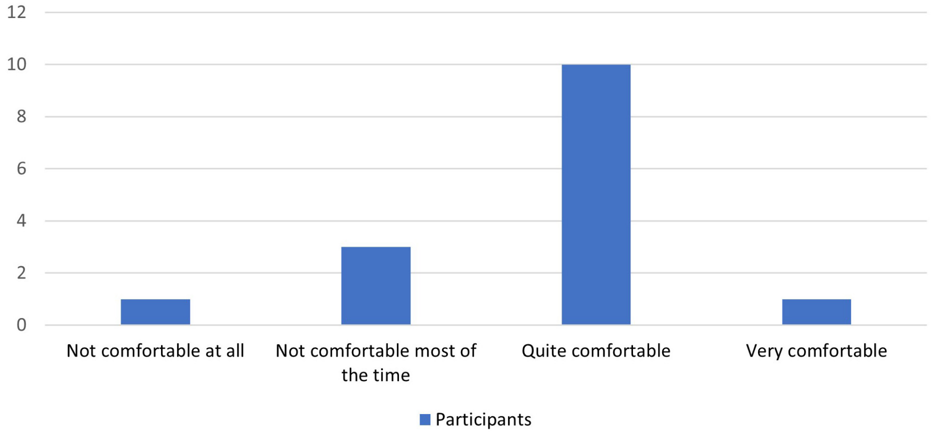


FIGURE 7
Feedback on the comfort level of using the Augmented Reality Games to Enhance Vocational Ability of Patients (REAP) augmented reality equipment.

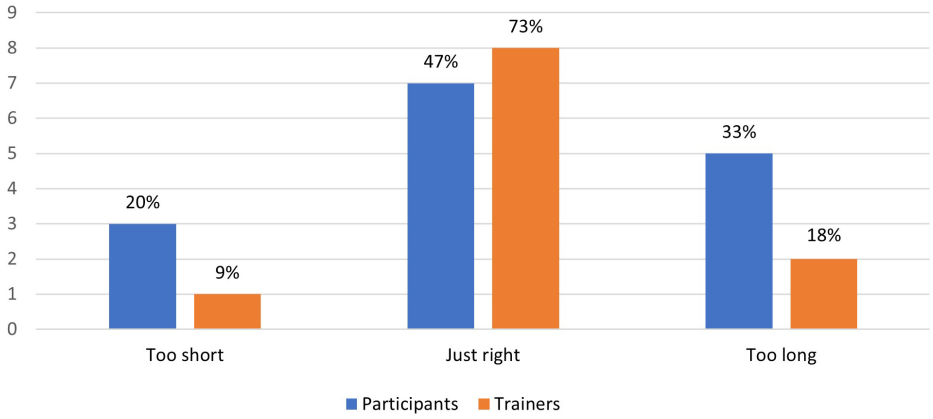


FIGURE 8
Feedback on the duration of the Augmented Reality Games to Enhance Vocational Ability of Patients (REAP) program.

demanding, as it entailed precise manipulation of the controller to point at the objects accurately.

In addition, both groups gave comments on how to maximize transfer of learning to real-life situations and provided suggestions for other virtual scenarios. They felt that opportunities should be given to try out customer service, remembering things, doing chores and food preparation in the daily lives, so as to maintain the skills learned. The participants and trainers also suggested other virtual scenarios such as packing items, data entry and housekeeping, so as to closely mimic participants' work experiences or to expand their repertoire of skills.

Tailoring the program to meet individual needs and contexts

The participants and trainers provided a range of comments regarding the difficulty level of different scenarios. Some participants felt that the "Sandwich Making" scenario was easy and the "Cashiering" scenario challenging, while others had the opposite experiences. Likewise, a few trainers felt that rehearsal strategies helped participants in remembering customers' orders at the cashier better, while other trainers observed this to be a frustrating experience for the participants.

In terms of perceived usefulness of the gamified platform, there were also differing opinions among the participants, as well as between participants and trainers. Some of the participants found the AR games more useful and interesting from the middle sessions onward, while others found the initial sessions more beneficial for them. Three trainers found the "Work Etiquette" scenario particularly useful, four trainers found the "Cashiering" scenario to be particularly useful, while four participants found the "Sandwich Making" scenario to be particularly useful. It appeared that the program catered to differing needs and interest levels and provided a good mix of challenges. Therefore, six trainers emphasized the need to tailor the program according to individual needs, through adjusting the duration of each session, number of sessions, number of cues and prompts, etc. They also felt that participants with lower cognitive functioning and poorer reading levels tend to struggle with the auditory and written instructions. Therefore, instructions would need to be presented slower, with more visual cues in the virtual environment to direct their attention appropriately.

> *"For participants with harder understanding: recommend guiding one time round in game as clients are more visual. Suggest at level 1, to show sandwich already prepared in shelf" (T06).*

In addition, trainers who were more involved in sheltered work found this program to be less applicable, thus highlighting the importance of contextualizing the program.

Technical aspects of the augmented reality platform

Four trainers and two participants highlighted technical aspects of the AR platform which could be improved, such as software bugs, sensitivity of the handheld control and inconsistent audio feedback. They also suggested the need to have a working second-player mode installed on the mobile device, for trainers to view the participants' engagement in the games concurrently. This would allow the trainers to monitor the participants' progress and to provide appropriate prompts more easily.

> *"It was difficult to see what is on the screen, especially when clients cannot find the laser pointer, so good to have two screens so that trainer knows what client is viewing on the screen and can help" (T02).*

In addition, eight participants and five trainers commented on the comfort and safety aspects of the AR platform. Although a few of them felt that the headset was comfortable enough, others found it too heavy after some time. Therefore, it was important to have a break every 10 min to reduce discomfort and prevent giddiness. Proper adjustment of the headset was also crucial to ensure that it was not too tight. In addition, three trainers stressed the need to have adequate space around the participants, to accommodate physical movements when the participants were navigating around the virtual environment. Lastly, five trainers commented that the use of an AR headset rendered it unsuitable to be used as a home program. A mobile application version would be required.

Discussion

This pilot study showed that adults with intellectual and developmental disabilities generally had positive experiences with a vocational training program that utilized a gamified augmented reality platform, coupled with intervention sessions to bridge real-life applications. In addition, participants who had engaged in this 10-week program showed a significant improvement in vocational skills and aspects of cognitive skills, which were maintained eight weeks after training. Vocational skills and cognitive skills were measured using Feasibility Evaluation Checklist (FEC) and Cognistat, respectively.

Acceptability of augmented reality vocational training program

Research on the user acceptability of AR gamified vocational training programs for adults with intellectual and developmental disabilities has been sparse. In the small-sample study on the AR-enabled vocational task prompting system

(ARCoach), the three research participants indicated that the mental and physical effort in operating the device was low and that they would recommend it to their peers (6). Similarly, 85.7% of the participants who used the "Paint-cAR" mobile application device to learn car paint repair also stated that they would like to use AR-enabled mobile applications to learn more vocational skills (14). Nevertheless, 50% of these participants reported that they hardly installed new mobile applications and would need technical support (14). In another study, adults with intellectual disabilities working in horticulture found it difficult to activate AR video instructions at selected locations due to navigation difficulties and they did not find the technology useful (13).

Our pilot study provided a more in-depth understanding of the feasibility and acceptability of gamified AR programs by conducting semi-structured interviews with both participants and vocational rehabilitation trainers. The AR platform used in the REAP program was displayed on a headset rather than a mobile device application. This provided a more immersive environment without the need for location-specific triggers. However, participants commented on the comfort level of the headsets, with some finding it heavy after a while and emphasized the need for proper adjustments of the headsets and to have frequent breaks to prevent giddiness. In general, majority of the participants and trainers found the REAP program to be useful and interesting. They also found the AR games to be user-friendly and the equipment to be relatively easy to handle.

Effectiveness of the augmented reality vocational training program

The qualitative data provided further insights into the acceptability and effectiveness of the REAP program. Seven participants and four trainers felt that the program trained aspects of cognitive functions, such as attention, memory, and problem-solving. This was reflected in their improvement in the memory and reasoning domain scores of the Cognistat. Although adults with intellectual disabilities had cognitive limitations, the use of a contextualized skills training program that promoted rehearsal and simple strategy building appeared to have helped these participants in performing cognitive tasks. Memory recall was specifically identified by participants as an area that they benefited in, as scenarios such as "Sandwich Making" and "Cashiering" required them to find ways to memorize sandwich ingredients or multiple orders from customers. When asked about cognitive strategies used during the game sessions, the trainers identified breaking down the tasks, verbalizing the ingredients aloud, using visual aids and giving verbal prompts as the commonly used strategies. Some of these strategies might have facilitated internal strategy learning process, while others might be compensatory in nature. Therefore, the participants could have picked up these strategies to varying degrees and applied them during the game sessions and across various tasks during bridging sessions. In the field of cognitive remediation within psychiatric rehabilitation, the use of strategies had also been shown to have a positive effect on functioning (36, 37). More research would be necessary to ascertain the strategy learning process of adults with intellectual and developmental disabilities.

In addition, the participants commented that they picked up soft skills and self-regulation skills during the REAP training program. As self-management skills could have an impact on work task performance (38), improvement in such skills could have enhanced the participants' interpersonal behavior and work productivity, which were components evaluated in the FEC. Correspondingly, the trainers reported that the REAP program taught participants new skills such as work etiquette, customer service and instruction-taking. Although participants might not be serving customers in the center, the AR games had provided opportunities for them to learn workplace interaction, executing work instructions and correct work habits in the virtual work environment. This could have led to an improvement in their total FEC scores, which were maintained eight weeks after the REAP program ended. Therefore, there is potential in using a well-integrated AR-enabled program to improve functional performance of adults with intellectual and developmental conditions.

A notable theme that emerged from the interviews was the importance of tailoring the program according to individual needs and contexts. There were differing opinions from participants and trainers about the useful aspects of the training scenarios, and they also had different perceptions of the scenarios' difficulty levels. It appeared that the REAP program catered to differing needs and interest levels and provided a good mix of challenges. Therefore, it would be beneficial for an AR-enabled vocational training program to offer a range of work tasks that are structured in various difficulty levels and to provide an array of visual and auditory cues. The vocational training staff will then have to conduct a functional assessment to determine the type of virtual work scenarios, the difficulty level, the type of cues and the intensity of sessions that best match the client's functional level and vocational goals.

From the results of the participants' game performance, it was found that there were no significant changes in the number of attempts per session, number correct attempts and the number of hints used across the sessions. Perhaps as the participants moved along the sessions, they attempted different training scenarios or moved up the difficulty levels. Therefore, they might not necessarily have accomplished more attempts or had more correct attempts. However, there were significant improvement in the number of correct multiple-choice responses, showing that some learning had taken place. There is currently no evidence on the minimal number of sessions required for an AR-enabled vocational training program for adults with intellectual and developmental conditions. In this study, a 10-week program was able to bring about some gains in vocational skills. More research would be needed to investigate the intensity required for persons of different levels of intellectual disabilities with diverse vocational goals.

The participants and trainers highlighted that the AR training scenarios provided a unique experience and gave opportunities to try things out in a virtual world, before implementing them in the real world. Through these virtual games, the trainers got to understand the type of cues and supports (e.g., written instructions, visual arrows, auditory prompts, flipping through the recipe book, etc.) that were effective with specific participants and were able to implement these cues in their standard work therapy within the center. During the COVID-19 pandemic when physical contact was restricted, AR games also provided an alternative source of work task engagement. Hence, AR may be a viable option for adults with intellectual disabilities to try out different "virtual jobs," to understand their job preferences and interests. Despite supported or open employment being the preferred employment model for adults with intellectual and developmental disabilities, many of them are still not able to access such employment opportunities and may only be able to attend sheltered workshops (39). Through exposure to various "virtual jobs," vocational staff can start to identify clients' strengths, interests and preferences and find similar vocational opportunities in the job market for clients to embark on.

Study limitations and recommendations for future research

This pilot study adopted a pretest–posttest mixed methods design, with a small sample size and no comparison group. An experimental study would be necessary to determine the effectiveness of a gamified augmented reality vocational training program, when compared against standard vocational rehabilitation. As this study recruited adults with intellectual disabilities and autism who also had co-morbid psychiatric conditions, the participants reported varying opinions on the useful aspects of the training scenarios. Future studies would be needed to have a thorough understanding of the therapeutic components that matched different adaptive functioning levels of this population of clients. Comparisons in responses between participants with intellectual disabilities and autism will also shed some light on the therapeutic ingredients of this program.

In addition, it would be useful to delve deeper into how therapeutic alliance and curriculum of the bridging group could affect training outcomes. As the trainers were working closely with the participants in the work therapy program within the center, they were assigned to administer the FEC. Future studies involving blinding of the raters would increase the internal validity of the research.

Literature on supported employment has shown that persons with intellectual disabilities not only experience barriers in obtaining employment, but also have difficulties in maintaining employment (40, 41). The use of AR-enabled vocational training for clients on supported employment has not been explored, but there is potential for its use as an adjunctive training to improve job sustainability.

Lastly, participants and trainers in this study reported technical issues on the AR platform and suggested enhancements such as using google glasses and having a second player mode. In addition, it was acknowledged that the hand grip movements used in manipulating the handheld controllers were not similar to the hand grips and pinches used in the real-life functional tasks of sandwich making and serving drinks. Therefore, a more realistic physical interaction with virtual objects would have improved user experience. A wider variety of virtual jobs and training scenarios could also have improved user satisfaction and increased its effectiveness. Future research could explore a wider repertoire of AR gamified vocational training scenarios, with additional features such as verbal interactions and haptic feedback.

Conclusion

This pilot study on the REAP program showed that a gamified augmented reality vocational training program was feasible and accepted by both adults with intellectual and developmental disabilities, as well as their vocational rehabilitation trainers. When integrated with bridging sessions to facilitate transfer of learning to existing work therapy, participants on the REAP program showed significant improvements in vocational skills and aspects of cognitive performance which were maintained eight weeks after the program ended. Future experimental studies with larger sample size could provide stronger evidence on its effectiveness in improving vocational outcomes.

Data availability statement

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

Ethics statement

The studies involving human participants were reviewed and approved by Singapore Institute of Technology Institutional Review Board (study number: 2020004). The participants provided their written informed consent to participate in this study.

Author contributions

B-LT, FG, and AM: conception and design. B-LT, IL, SK, OD, and FG: development of REAP vocational training program. B-LT, IL, and SK: data analysis. All authors wrote the manuscript and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2022.966080/full#supplementary-material

SUPPLEMENTARY DATASHEET 1
User Feedback Semi-Structured Interview Form for Participants.

SUPPLEMENTARY DATASHEET 2
User Feedback Semi-Structured Interview Form for Vocational Trainers.

References

1. Standen PJ, Rees F, Brown DJ. Effect of playing computer games on decision making in people with intellectual disabilities. *J Assist Technol.* (2009) 3:6–15. doi: 10.1108/17549450200900011

2. Green JM, Hughes EM, Ryan JB. The use of assistive technology to improve time management skills of a young adult with an intellectual disability. *J Special Educ Technol.* (2011) 26:13–20. doi: 10.1177/016264341102600302

3. Clyne C, Jackman C, Tully M, Coyle D, O'Reilly G. We live in the moment"—experiences of people with intellectual disabilities and clinicians of computer-assisted mindfulness and relaxation. *Br J Learn Disabil.* (2022). doi: 10.1111/bld.12386

4. Nicholson S. A recipe for meaningful gamification. In: Reiners T, Wood L editors. *Gamification in Education and Business.* Cham: Springer (2015). p. 1–20. doi: 10.1007/978-3-319-10208-5_1

5. Montoya-Rodríguez MM, de Souza Franco V, Tomás Llerena C, Molina Cobos FJ, Pizzarossa S, García AC, et al. Virtual reality and augmented reality as strategies for teaching social skills to individuals with intellectual disability: a systematic review. *J Intellect Disabil.* (2022):174462952210891. doi: 10.1177/17446295221089147 [Epub ahead of print].

6. Chang YJ, Kang YS, Huang PC. An augmented reality (AR)-based vocational task prompting system for people with cognitive impairments. *Res Dev Disabil.* (2013) 34:3049–56. doi: 10.1016/j.ridd.2013.06.026

7. Chan ZYS, MacPhail AJC, Au IPH, Zhang JH, Lam BMF, Ferber R, et al. Walking with head-mounted virtual and augmented reality devices: effects on position control and gait biomechanics. *PLoS One.* (2019) 14:e0225972. doi: 10.1371/journal.pone.0225972

8. Sahin NT, Keshav NU, Salisbury JP, Vahabzadeh A. Safety and lack of negative effects of wearable augmented-reality social communication aid for children and adults with autism. *J Clin Med.* (2018) 7:188. doi: 10.3390/jcm7080188

9. Bridges SA, Robinson OP, Stewart EW, Kwon D, Mutua K. Augmented reality: teaching daily living skills to adults with intellectual disabilities. *J Special Educ Technol.* (2020) 35:3–14. doi: 10.1177/0162643419836411

10. McMahon D, Cihak DF, Wright R. Augmented reality as a navigation tool to employment opportunities for postsecondary education students with intellectual disabilities and Autism. *J Res Technol Educ.* (2015) 47:157–72. doi: 10.1080/15391523.2015.1047698

11. Smith CC, Cihak DF, Kim B, McMahon DD, Wright R. Examining augmented reality to improve navigation skills in postsecondary students with intellectual disability. *J Special Educ Technol.* (2017) 32:3–11. doi: 10.1177/0162643416681159

12. Kang YS, Chang YJ. Using an augmented reality game to teach three junior high school students with intellectual disabilities to improve ATM use. *J Appl Res Intellect Disabil.* (2020) 33:409–19. doi: 10.1111/jar.12683

13. Benda P, Ulman M, Šmejkalová M. Augmented reality as a working aid for intellectually disabled persons for work in horticulture. *Agris Online Papers Econo Inform.* (2015) 7:31–7. doi: 10.7160/aol.2015.070403

14. Bacca J, Baldiris S, Fabregat R, Kinshuk, Graf S. Mobile augmented reality in vocational education and training. *Proc Comput Sci.* (2015) 75:49–58. doi: 10.1016/j.procs.2015.12.203

15. Cheng C, Oakman J, Bigby C, Fossey E, Cavanagh J, Meacham H, et al. What constitutes effective support in obtaining and maintaining employment for individuals with intellectual disability? A scoping review. *J Intellect Dev Disabil.* (2018) 43:317–27. doi: 10.3109/13668250.2017.1327040

16. Lysaght R, Ouellette-Kuntz H, Lin CJ. Untapped potential: perspectives on the employment of people with intellectual disability. *Work.* (2012) 41:409–22. doi: 10.3233/WOR-2012-1318

17. Chandrasekaran P, Thekkumkara SN, Jothibalan A, Jagannathan A, Jayarajan D, Reddy SK. Hybrid supported employment approach for persons with intellectual disabilities in india: evidence based case studies. *J Psychosoc Rehabil Ment Health.* (2021):1–7. doi: 10.1007/s40737-021-00241-9 [Epub ahead of print].

18. Chiam BSW, Leung IMW, Devilly OZ, Ow CYD, Guan FY, Tan BL. Novel augmented reality enhanced solution towards vocational training for people with mental disabilities. *Proceedings of the 2021 IEEE International Symposium on Mixed and Augmented Reality Adjunct, ISMAR-Adjunct.* (Vol. 2021), Bari: (2021). p. 195–200.

19. Nicholson S. A User-centered theoretical framework for meaningful gamification a brief introduction to gamification. *Paper Presented at Games+Learning+Society 8.0.* Madison, WI: (2012).

20. Medalia A, Herlands T, Saperstein A, Revheim N. *Cognitive Remediation for Psychological Disorders: Therapist Guide Treatments That Work.* Oxford: Oxford University Press (2017). doi: 10.1093/med-psych/9780190608453.001.0001

21. Medalia A, Saperstein A. Does cognitive remediation for schizophrenia improve functional outcomes? *Curr Opin Psychiatry.* (2013) 26:151–7. doi: 10.1097/YCO.0b013e32835dcbd4

22. Nott MT, Chapparo C, Heard R. Reliability of the perceive, recall, plan and perform system of task analysis: a criterion-referenced assessment. *Aust Occup Ther J.* (2009) 56:307–14. doi: 10.1111/j.1440-1630.2008.00763.x

23. Mills C, Chapparo C. Use of perceive, recall, plan, perform stage two cognitive task analysis for students with autism and intellectual disability: the impact of a sensory activity schedule. *J Occup Ther Sch Early Interv.* (2017) 10:232–53. doi: 10.1080/19411243.2017.1335262

24. Medalia A, Freilich B. The neuropsychological educational approach to cognitive remediation (NEAR) model: practice principles and outcome studies. *Am J Psychiatr Rehabil.* (2008) 11:123–43. doi: 10.1080/15487760801963660

25. Haas JK. *A History of the Unity Game Engine.* (2014). Available online at: http://citebay.com/how-to-cite/unity/

26. Kiernan RJ, Mueller J, Langston JW, Van Dyke C. The neurobehavioral cognitive status examination: a brief but quantitative approach to cognitive assessment. *Ann Intern Med.* (1987) 107:481–5. doi: 10.7326/0003-4819-107-4-481

27. Kim EJ, Bahk YC, Oh H, Lee WH, Lee JS, Choi KH. Current status of cognitive remediation for psychiatric disorders: a review. *Front Psychiatry.* (2018) 9:461. doi: 10.3389/fpsyt.2018.00461

28. Cheung JCW, Ni M, Tam AYC, Chan TTC, Cheung AKY, Tsang OYH, et al. Virtual reality based multiple life skill training for intellectual disability: a multicenter randomized controlled trial. *Eng Regen.* (2022) 3:121–30. doi: 10.1016/j.engreg.2022.03.003

29. Matheson L. Measuring work performance from an occupational performance perspective. In: Law M, Baum C, Dunn W editors. *Measuring Occupational Performance.* Thorofare, NJ: SLACK Incorporated (2001).

30. Matheson LN. *Feasibility Evaluation Checklist: A Measure of Vocational Readiness Professional Manual.* St. Charles, MI: EpicRehab (2011).

31. Doninger NA, Ehde DM, Bode RK, Knight K, Bombardier CH, Heinemann AW. Measurement properties of the neurobehavioral cognitive status examination (Cognistat) in traumatic brain injury rehabilitation. *Rehabil Psychol.* (2006) 51:281–8. doi: 10.1037/0090-5550.51.4.281

32. Johansson MM, Kvitting AS, Wressle E, Marcusson J. Clinical utility of cognistat in multiprofessional team evaluations of patients with cognitive impairment in Swedish primary care. *Int J Fam Med.* (2014) 2014:649253. doi: 10.1155/2014/649253

33. Ibm. *SPSS Statistics for Windows. Version 28.0.* Armonk, NY: IBM (2021).

34. Quirkos 2.4.2. *Computer Software.* (2021). Available online at: https://www.quirkos.com

35. Patton MQ. *Qualitative Research & Evaluation Methods.* 4th ed. Saint Paul, MN: Sage Publications (2015).

36. Wykes T, Huddy V, Cellard C, McGurk SR, Czobor P. A meta-analysis of cognitive remediation for schizophrenia: methodology and effect sizes. *Am J Psychiatry.* (2011) 168:472–85. doi: 10.1176/appi.ajp.2010.10060855

37. Mcgurk SR, Twamley EW, Sitzer DI, Mchugo GJ, Mueser KTA. Meta-analysis of cognitive remediation in schizophrenia. *Am J Psychiatry.* (2007) 164:1791–802. doi: 10.1176/appi.ajp.2007.07060906

38. Barczak MA, Cannella-Malone HI. Self-management of vocational skills for people with significant intellectual disabilities: a systematic review. *J Intellect Disabil.* (2022) 26:470–490. doi: 10.1177/1744629520987768

39. Wehman P, Taylor J, Brooke V, Avellone L, Whittenburg H, Ham W, et al. Toward competitive employment for persons with intellectual and developmental disabilities: what progress have we made and where do we need to go. *Res Pract Persons Sev Disabil.* (2018) 43:131–44. doi: 10.1177/1540796918777730

40. Ellenkamp JJH, Brouwers EPM, Embregts PJCM, Joosen MCW, van Weeghel J. Work environment-related factors in obtaining and maintaining work in a competitive employment setting for employees with intellectual disabilities: a systematic review. *J Occup Rehabil.* (2016) 26:56–69. doi: 10.1007/s10926-015-9586-1

41. Meltzer A, Robinson S, Fisher KR. Barriers to finding and maintaining open employment for people with intellectual disability in Australia. *Soc Policy Administ.* (2020) 54:88–101. doi: 10.1111/spol.12523

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Prevalence and correlates of post-traumatic stress disorder and its symptomatology in tornado-affected rural residents

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Experiencing a serious natural disaster may place survivors at particularly high risk for post-traumatic stress disorder (PTSD); however, very limited data are available on the prevalence and clinical characteristics of PTSD among survivors of a tornado disaster. The present study examined the prevalence of PTSD and correlates and clinical symptoms of possible PTSD in survivors 1.5 months after a tornado disaster. A total of 237 survivors were recruited and administered the Structured Clinical Interview for DSM-V (SCID) to measure the prevalence of PTSD and the Essen Trauma Inventory (ETI) to measure the incidence of symptoms in each dimension. Survivors'demographic information and characteristics of exposure to the tornado were collected via self-report questionnaires. Thirty-two of the survey respondents were diagnosed with PTSD (13.6%, total =237). Correlates of PTSD in survivors were being female (OR=3.62, $P = 0.023$), living in an area severely affected by the tornado (OR = 3.94, $P = 0.032$), and having severe property damage (OR = 3.72, $P = 0.010$). Less common symptoms mainly focused on the avoidance dimension and included feeling alienated or distant from the people around oneself (21.90%), not being able to recall important parts of the event (28.10%), being emotionally numb (31.20%), and feeling like one's plans for the future and hopes will not come true (37.50%). In the sample of rural residents, nearly two-thirds of people with PTSD were not willing to seek psychological help; increasing the accessibility of mental health services and administering more active mental health services are necessary for this vulnerable population, whether or not they claim to need help.

KEYWORDS

tornado disaster, post-traumatic stress disorder, structured clinical interview for DSM-V (SCID), symptoms, correlates, prevalence

Introduction

At 20:39 on 14 May 2021, a 17-magnitude tornado broke out in Wuhan City, Hubei Province. The wind speed reached a maximum of 60 m/s; some houses in the village bay were damaged, a large number of trees were fractured, and some work sheds collapsed. As of May 15, 2021, the tornado had killed 8 people and injured approximately 280 people. The disaster not only resulted in physical and tangible damage to the local people affected by the disaster but also caused serious psychological challenges. Relevant studies have shown that after major traumatic disaster events, disaster victims experience symptoms such as depression (1, 2), anxiety (1), sleep disturbance (3, 4), and symptoms of post-traumatic stress disorder (PTSD) (5). Severe cases are also diagnosed as PTSD (6), which greatly affects postdisaster reconstruction and the mental health of victims. From 23 June 2021 to 27 June 2021, members of the research team went to Zhashan, Caidian District, Wuhan City, Hubei Province, to conduct the research.

Subjects and methods

The research group went to Caidian District, Wuhan City, Hubei Province from 23 June 2021 to 27 June 2021. A total of 240 questionnaires were distributed, and 237 valid questionnaires were recovered, with an effective rate of 98.3%. This study took rural residents affected by the tornado disaster as the research sample, analyzed PTSD and its symptoms in rural residents after the disaster, and analyzed its correlating factors. The detection of the symptoms of each dimension of PTSD was explored.

Research subjects

The Respondents Were Rural Residents of three Rural Villages in Zhashan in the Tornado-affected area of Caidian District, Wuhan City. The local government classified villages according to the degree to which they were affected by the tornado: mildly affected (village A, village B, village C, village D, village E, village F, and village G) and severely affected (village H, village I and village J). According to this classification, two mildly affected villages (village B and village E) and one severely affected village (village I) of the two disaster degrees were selected as the target group by stratified sampling. In the three randomly selected villages, the method of random sampling was adopted, and 1/6 families in each village were selected as the research sample. Random sampling was carried out in each family according to the criteria of age no <12 years old and birthday close to 15 June to ensure the reliability of the sample. One sample was taken from each family.

The Institutional Review Board of Wuhan Mental Health Center approved the study protocol, and all participants signed informed consent forms.

Research methods

The investigators were postgraduates majoring in psychology and psychiatry. All investigators underwent unified centralized training and had extensive research experience. The researchers first introduced the purpose and specific methods of the assessment to the respondents and then conducted a questionnaire survey after obtaining the respondents' informed consent. The survey was conducted in a one-on-one, question-and-answer format, and all tests were conducted using uniform guidelines. The results of the questionnaires were stored in a unified and centralized manner to ensure the confidentiality of the survey data.

Research instruments

The research questionnaire used the Essen Trauma Inventory (ETI) to assess PTSD symptoms (7). The affected rural villagers were diagnosed with PTSD using the Structured Clinical Interview for DSM-V (SCID) (8) (the researcher conducting the PTSD diagnosis was trained in the SCID interview by the Wuhan Mental Health Center).

PTSD

The SCID was used to diagnose PTSD. It is the most widely used structured diagnostic tool for assessing mental illness. It can be used to assess mood disorders, psychotic disorders, substance abuse disorders, anxiety disorders, obsessive-compulsive disorders and related disorders, eating disorders, somatic symptom disorders, some sleep disorders (such as insomnia and somnolence disorders), externalizing behavior disorders (i.e., intermittent explosive disorder, gambling disorder and adult attention deficit hyperactivity disorder) and trauma and stress-related disorders.

PTSD symptoms

The validated Chinese version of the ETI was used to assess three symptom clusters of PTSD. The ETI was developed based on the DSM-IV-TR diagnostic criteria, and it has five parts with a total of 58 items. Part 1 contains a list of 14 potentially traumatic events and an open question asking about exposure to other traumatic events. Part 2 has 10 questions regarding the worst event's objective and subjective threat to life (criteria A1 and A2). Part 3 consists of 23 questions covering three symptom clusters of PTSD (intrusion [criteria B], avoidance [criteria C], and hyperarousal [criteria D]) and one additional symptom cluster for ASD (dissociation). Part 4 assesses the severity of psychological distress caused by the event [criteria

TABLE 1 Demographic information and characteristics of exposure to the tornado of rural residents who survived the tornado disaster.

Factors		*n*	Ratio(%)
Demographic			
Gender	Male	129	54.70%
	Female	107	45.30%
Age	28-40	14	5.90%
	41-60	97	41.10%
	61-83	125	53.00%
Education	Illiterate	28	11.90%
	Primary school	68	28.80%
	Junior middle school	95	40.30%
	High school	40	16.90%
	Undergraduate and above	5	2.10%
Marital status	Married	205	87.20%
	Unmarried	8	3.00%
	Divorced	7	3.00%
	Widowed	16	6.80%
Living arrangements	Living alone	27	11.40%
	Group quarters	2	0.80%
	Living with relatives	205	86.50%
	Other	2	0.80%
Personal monthly income	Low	156	66.40%
	Middle	76	31.90%
	High	4	1.70%
Smoking	Never or hardly smoke	162	68.70%
	Quit smoking	9	3.80%
	Smoking	65	27.50%
Frequency of alcohol consumption	Never	184	78.00%
	Occasionally	38	16.10%
	Often	8	3.40%
	Almost every day	6	2.50%
Exposure to the tornado disaster			
Disaster degree	Living in a mildly affected area	141	59.70%
	Living in a severely affected area	95	40.30%
Property damage	Slight property damage	161	68.20%
	Severe property damage	75	31.80%
Physical injury	Yes	11	4.70%
	No	225	95.30%
Witness any injuries or deaths	No	193	81.80%
	Yes	43	18.20%

$n = 23$.

F] and the duration of PTSD symptoms [criteria E]. Part 5 evaluates the severity of functional impairment caused by the event in terms of life satisfaction, school/work/job performance, household chores and duties, hobbies and leisure activities, relationships with friends, family relationships, and sexual life [criteria F].

Demographics

Demographic variables included gender, age, education, marital situation, living arrangements, personal income, smoking and alcohol consumption.

Exposure to the tornado disaster

Classification of the disaster degree and three questions were used to assess the severity of exposure to the tornado: "Did the disaster cause serious property damage?", "Were you physically harmed by the disaster?", and "Did you witness any injuries or deaths in the disaster?".

Willingness to ask for psychological assistance

Two questions were used to assess the willingness to ask for psychological assistance: "Do you have any psychological troubles?", "If so, do you need psychological assistance? (e.g., counseling, psychotherapy, and medication)."

Statistical analysis

The questionnaire data were analyzed using SPSS 21.0 statistical software. Before data analysis, the normality of the data was tested by combining histograms and P-P plots of the data distribution, and the results showed that the data generally followed a normal distribution. Detection rates for PTSD were calculated, and rates between subgroups were compared using chi-square tests based on demographic and tornado disaster exposure characteristics. Significant factors from the chi-square test were included in binary logistic regression to determine the factors associated with PTSD. Associations between correlates and PTSD were quantified using OR values and 95% confidence intervals. PTSD symptoms in affected villagers were described using frequencies and percentages. A two-sided $P < 0.05$ was considered statistically significant.

Results

General information of all respondents

Among the 237 affected rural villagers surveyed, information on their demographics (eight items) and tornado exposure characteristics (four items) was collected with a total of 12 items. The general information is shown in Table 1. Of all survey respondents, 32 were diagnosed with PTSD based on the SCID, accounting for 13.6% of the total survey population. Of the 95 most severely affected samples, 27 (28.4%) were diagnosed with PTSD. It was found that people with PTSD were more likely to be willing to seek psychological help (psychological counseling, psychotherapy, psychopharmacological treatment) than those without PTSD ($\chi^{2}= 35.075$, $P < 0.001$), but nearly 2/3 of people with PTSD (68.75%) still did not seek help (Table 2).

Analysis of the factors correlated with PTSD

The results of the chi-square test showed that those who were female, had severe property damage, were physically injured, were severely affected by the disaster, and witnessed injuries or deaths were more likely to have a diagnosis of PTSD. ($P < 0.05$) (Table 3).

The inclusion of the factors associated with the diagnosis of PTSD from the chi-square test results in a binary logistic regression showed that being female (OR = 3.62, $P = 0.023$), living in area severely affected by the tornado (OR = 3.94, $P = 0.032$) and having severe property damage (OR = 3.72, $P = 0.010$) were risk factors for the diagnosis of PTSD (Table 4).

TABLE 2 Results of the willingness to ask for psychological assistance.

		Willingness to ask for psychological assistance		
		No	**Yes**	**Total**
diagnosed with PTSD	Negative	198	6	204
	Positive	22	10	32
Total		220	16	236

Detection of PTSD symptoms by symptom cluster

Table 5 shows the detection of symptoms for each dimension of PTSD among the respondents. The most common symptoms in the intrusion, avoidance and hyperarousal dimensions were feeling emotionally upset when one was reminded of the event (75.00%), trying to avoid situations that reminded one of the event (56.30%), and being overly alert (75.10%), respectively. Less common symptoms mainly focused on the avoidance dimension and included feeling alienated or distant from the people around oneself (21.90%), not being able to recall important parts of the event (28.10%), being emotionally numb (31.20%), suddenly feeling like one is living through the event again (31.30%), and feeling like one's plans for the future and hopes will not come true (37.50%). See Table 5.

Discussion

This study was a field study in the affected rural villages of Caidian District conducted 1.5 months after the tornado in Caidian District, Wuhan City. The prevalences of PTSD were found to be 13.6% overall and 28.4% in the most severely affected rural villages. Risk factors for PTSD diagnosis were being female, living in a severely affected area, and having severe property damage. Compared to the typical PTSD symptoms according to the DSM-V-TR criteria, the avoidance dimension was less frequent than the other two dimensions, particularly feeling alienated or distant from the

TABLE 3 Results of the chi-square test on collected factors in rural residents who survived the tornado disaster.

Factors		***n***	**Number of persons diagnosed with PTSD (%)**	**X^2**	***P***
Demographic					
Gender	Male	129	9(6.98%)	10.52	0.001
	Female	107	23(21.50%)		
Exposure to the tornado disaster					
Property damage	Slight property damage	161	11(6.83%)	19.56	<0.001
	Severe property damage	75	21(28.00%)		
Physical injury	Yes	11	6(54.55%)	16.54	<0.001
	No	225	26(11.56%)		
Disaster degree	Living in a mildly affected area	141	5(3.55%)	29.96	<0.001
	Living in a severely affected area	95	27(28.42%)		
Witness any injuries or deaths	No	193	22(11.40%)	4.22	0.040
	Yes	43	10(23.26%)		

people around oneself (21.90%), not being able to recall important parts of the event (28.10%), and being emotionally numb (31.20%).

In the general Chinese population, the 1-month prevalence of PTSD was 0.195% (9), which was significantly lower than the 1-month prevalence of PTSD in the affected villagers in this study (13.60%). Previous studies on the detection rate of PTSD after disaster events have also shown varying results, with the prevalence of PTSD after earthquakes, rockfalls, mudslides and car accidents ranging from 18.80 to 43.00% (10–13). The detection rate of PTSD among the affected villagers in this study was slightly higher than the rates after tornado disasters in previous studies (14, 15). The reasons for this phenomenon may be related to the status and older age of rural residents. First, rural elderly people have more severe mental health problems overall than urban elderly people (16). Second, the affected villagers were generally older (60.60 ± 11.70). The relationship between PTSD and age in previous studies is complex and may be related to the social, economic and cultural aspects of the affected areas (17), which may indicate that PTSD shows a positive correlation with age in rural areas of China. This also suggests that we need to consider the corresponding characteristics of the population when carrying out postdisaster psychological reconstruction.

TABLE 4 Results of binary logistic regression on factors associated with PTSD in rural residents who survived the tornado disaster.

Factors		OR(95%)	P
Demographic			
Gender	Male		
	Female	2.82(1.13,7.01)	0.026
Exposure to the tornado disaster			
Disaster degree	Living in a mildly affected area		
	Living in a severely affected area	4.51(1.46,13.92)	0.009
Property damage	Slight property damage		
	Severe property damage	3.72(1.38,10.05)	0.010

Among the demographic factors, women were at significantly higher risk for PTSD than men, which is consistent with previous research findings (18). Evidence suggests that direct trauma from disasters is an important determinant of PTSD development (18, 19). The results of this study also suggest that the degree of the disaster and property damage from the tornado disasters are significantly associated with PTSD diagnosis. In particular, the prevalence of PTSD was significantly higher in the sample from severely affected areas with severe property damage than in the sample from mildly affected areas with mild property damage. In

TABLE 5 PTSD symptoms of rural residents who survived the tornado disaster.

Symptom	*n*(often or very of 10)	%
Intrusion		
Did the event cause upset thoughts or images that came to your mind although you didn't want them to?	18	56.20%
Did you have nightmares about the event?	13	40.70%
Has it ever happened to you that you suddenly felt like you were living through the event again?	10	31.30%
Did you feel emotionally upset when you were reminded of the event (feeling helpless, angry, sad, guilty)?	24	75.00%
Have you ever had physical reactions when you were reminded of the event (e.g., uneasiness, chills, or fast heartbeat)?	16	50.10%
Avoidance		
Have you tried not to think about the event, not to talk about it, or to suppress feelings about it?	15	46.90%
Did you try to avoid situations that remind you of the event (e.g., activities, people, or places)?	18	56.30%
Were you unable to remember an important part of the event?	9	28.10%
Did you lose interest in activities that had been important to you before the event took place (e.g., hobbies, sports)?		
Did you feel alienated or isolated from people in your environment?	7	21.90%
Did you feel emotionally numb (e.g., being unable to cry or unable to have positive feelings)?	10	31.20%
Did you feel like your plans for the future and hopes would not come true (e.g., to start a family, less luck in life or in business than the others)?	12	37.50%
Hyperarousal		
Did you have trouble falling or staying asleep?	21	65.60%
Did you have fits of rage or were you often nervous?	14	43.70%
Did you have trouble concentrating (e.g., forgetting what you just wanted to do or forgetting what you just read or what you saw on television)?	13	40.60%
Were you overly alert (e.g., checking to see who is around you, having a phone close-by to call for help if necessary)?	24	75.10%
Were you easily startled or highly nervous (e.g., by loud noises)?	19	59.40%

addition, the study also investigated the willingness of the sample to seek psychological help. The results show a low overall willingness to seek help among affected people, reflecting the fact that crisis interventions may not be well received by some rural residents in the aftermath of a tornado disaster.The results also showed that individuals diagnosed with PTSD were more likely to seek psychological assistance, which could include counseling, psychotherapy, and medication. This suggests that PTSD patients suffer from the pain generated by the illness, which to some extent motivates their willingness to seek psychological assistance. In postdisaster psychological reconstruction, it is important to focus on and properly deal with victims who need help, as they are more likely to be potential PTSD sufferers. Although people with PTSD are more likely to be willing to seek psychological help, nearly two-thirds of people with PTSD are not. This may be due to a sense of stigma or a lack of knowledge about psychological assistance. Therefore, in addition to increasing the accessibility of mental health services and administering more active mental health services after a disaster, publicity and dissemination of mental health knowledge should be enhanced in rural areas before a disaster occurs to raise rural residents' awareness of mental health and crisis intervention with a view to reducing their sense of stigma about psychological problems.

In general, symptoms of PTSD vary from person to person, but intrusion, avoidance, and hyperirritability are typical symptoms (19). In the present study, most PTSD symptoms were present among the affected villagers according to the DSM-V-TR criteria, but symptoms in the avoidance dimension were less common than other symptoms. This may be because the damage to their houses caused by the disaster, as well as physical injuries, were real situations that they needed to face continuously and could not escape. In addition, interpersonal interaction was higher in rural areas than in urban areas, and the process of interacting with each other made it easier for individuals to deal with the disaster that had occurred.

This study has some limitations. First, this study adopted a cross-sectional study design, but the development of PTSD and its influencing factors are complex processes that change over time. Therefore, a follow-up longitudinal study can be carried out. Second, the sample size of this study is small, and more samples can be included later to increase the reliability of the research results. Third, SCID can not only diagnose PTSD, but also other mental disorders. For instance, MDD is highly prevalent among individuals that were affected by a disaster. This research only discuss the PTSD situation. Future studies could include other parts of the SCID for the diagnosis of other mental disorders. Lastly, The investigators found that social support and post-disaster negative life events had a significant impact on the affected people's understanding of the disaster, so the Social Support and Post-Disaster Negative Life Events could be surveyed to explore the impact of social support and post-disaster negative life events on changes in the mental health of the affected people.

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 the Institutional Review Board of Wuhan Mental Health Center. The patients/participants provided their written informed consent to participate in this study.

Author contributions

T-MW completed the manuscript draft. All authors contributed to the article and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2022.946450/full#supplementary-material

References

1. Norris FH, Friedman MJ, Watson PJ, Byrne CM, Diaz E, Kaniasty K. 60,000 disaster victims speak: Part I. an empirical review of the empirical literature, 1981-2001. *Psychiatry*. (2002) 65: 207–39. doi: 10.1521/psyc.65.3.207.20173

2. Shannon MP, Lonigan CJ. Finch AJ, Taylor CM. Children exposed to disaster: i epidemiology of post-traumatic symptoms and symptom profiles. *J Am Acad Child Adolesc Psychiatry.* (1994) 33:80–93. doi: 10.1097/00004583-199401000-00012

3. Wang Z, Sha W, Gu X, Bian J, Ye Q, Zhang X, et al. Investigation on the psychological status of the wounded and their families in Wenchuan earthquake stricken areas in Sichuan. *J Psychiatry.* (2009) 22:193–4.

4. North CS, Nixon SJ. Shariat S, Mallonee S, McMillen JC, Spitznagel EL, et al. Psychiatric disorders among survivors of the Oklahoma City Bombing. *JAMA.* (1999) 282:755–62. doi: 10.1001/jama.282.8.755

5. Ge F, Fan F, Zhang L. 18 months after the Wenchuan earthquake, adolescents in Dujiangyan area suffered from PTSD, depression and anxiety. *Chin J Clin Psychol.* (2012) 20:172–5. doi: 10.16128/j.cnki.1005-3611.2012.02.036

6. Zhou X, Wu X, Yuan X, Chen J, Chen Q. The relationship between trauma exposure and post-traumatic stress disorder in adolescents – the role of core belief challenge, subjective fear and invasive rumination. *J Psychol.* (2015) 47:455–65. doi: 10.3724/SP.J.1041.2015.00455

7. First MB. Structured clinical interview for the DSM (SCID). In*: The Encyclopedia of Clinical Psychology.* (2014). p. 1–6. doi: 10.1002/9781118625392.wbecp351

8. Huang Y, Wang YU, Wang H, Liu Z, Yu X, Yan J, et al. Prevalence of mental disorders in China: a cross-sectional epidemiological study. *Lancet Psychiatry.* (2019) 6:211–24. doi: 10.1016/S2215-0366(18)30511-X

9. Zhou J, Jin C, Zhang S, Wu C, Li F. Investigation report on mental reaction after rock avalanche and suspension bridge events in Wuxi County. *Chin Mental Health J*. (1988) 02:72–5.

10. He M, Wu R, Zhang X, Ji S, Chu M, Yang D. Post-traumatic stress disorder among rollover survivors. *Chin Mental Health J*. (1993) 190:148–51.

11. Zhao G, Yang Y, Zhang Q, Zhang S, Deng H, Zhu Y, et al. Incidence and influencing factors of post-traumatic stress disorder in community residents in Wenchuan earthquake stricken areas. *Chin Mental Health J.* (2009) 23:478–83. doi: 10.3969/j.issn.1000-6729.2009.07.008

12. Shi T, Jiang C, Jia S, Liu Q, Zhang J, Qi X. Evaluation scale of post-traumatic stress disorder in severe acute respiratory syndrome. *Clin Rehabil*. (2005) 9:44–7.

13. Adams ZW, Sumner JA, Danielson CK, McCauley JL, Resnick HS, et al. Prevalence and predictors of PTSD and depression among adolescent victims of the Spring 2011 tornado outbreak. *J Child Psychol Psychiatry*. (2014) 55: 1047–55. doi: 10.1111/jcpp.12220

14. Wang B, Wang X, Zhao F, Zhang L. Investigation on post-traumatic stress disorder of tornado wounded. *J PLA Hospital Manag.* (2020) 28:408–10. doi: 10.16770/J.cnki.1008-9985.2021.05.003

15. Ye B, Chen L, Gao J, Fu H. Relationship between perception of age discrimination and depressive symptoms in middle-aged and elderly people in rural areas. *Chin Mental Health J.* (2019) 33:524–9. doi: 10.3969/j.issn.1000-6729.2019.07.011

16. Norris FH, Kaniasty K, Conrad ML, Inman GL, Murphy AD. Placing age differences in cultural context: a comparison of the effects of age on PTSD after disasters in the United States, Mexico, and Poland. *J Clin Geropsychol.* (2002) 8:153–73. doi: 10.1023/A:1015940126474

17. Sareen J. Post-traumatic stress disorder in adults: impact, comorbidity, risk factors, and treatment. *Can J Psychiatry.* (2014) 59:460–7. doi: 10.1177/070674371405900902

18. Scott ST. Multiple traumatic experiences and the development of post-traumatic stress disorder. *J Interpers Violence.* (2007) 22:932–8. doi: 10.1177/0886260507301226

19. Meneses E, Kinslow K, McKenney M, Elkbuli A. Post-traumatic stress disorder in adult and pediatric trauma populations: a literature review. *J Surg Res.* (2021) 259:357–62. doi: 10.1016/j.jss.2020.09.023

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Attitudes toward and patterns of medication use among people with serious mental illness: There's more than meets the eye

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Background and aim: There are growing concerns about the long-term effects of psychiatric medication after a major psychiatric crisis. Recent evidence shows a diverse impact of long-term use on various outcome domains, which may help explain why non-adherence is so common. In the current study we explored the subjective perceptions of factors that impact both attitudes toward and patterns of use of medication among individuals with serious mental illness (SMI).

Method: Sixteen individuals with an SMI and a recognized psychiatric disability who had used psychiatric medication for at least 1year were recruited for the study *via* mental health clinics and social media. Participants were interviewed using a semi-structured interview based on the narrative approach, focusing on attitudes toward and patterns of use of psychiatric medication. All interviews were transcribed and analyzed using thematic analysis.

Results: Three discrete sequential phases emerged, each characterized by different themes referring to attitudes toward medication and patterns of use: (1) "loss of self" and a high level of medication use; (2) accumulating experiences of using/reducing/stopping medication; and (3) forming more stable attitudes toward medication and developing one's own pattern of use. The transition between phases was dynamic in nature and represents a non-linear process. Complex interactions were generated at different phases between the related themes, which shaped attitudes toward medication and patterns of use.

Conclusions and implications: The current study reveals the complex ongoing process of forming attitudes toward medication and patterns of use. Recognizing and identifying them *via* a joint reflective dialog with mental health professionals can enhance alliance, shared decision-making, and person-centered recovery-oriented care.

KEYWORDS

attitudes toward medication, adherence to psychiatric medication, serious mental illness, recovery, narrative interviews, qualitative research

Introduction

In accordance with treatment guidelines, psychiatric medication is recommended as the core treatment for individuals with serious mental illness (SMI; 1, 2). Yet approximately half of those who are prescribed medication do not adhere to treatment, according to a recent systematic review (3). Non-adherence is associated with a host of negative outcomes including symptom exacerbation, more emergency room visits and psychiatric hospitalizations, and high mortality rates (4–6). A common assumption as to why people do not use medications from which they could benefit is that they lack "insight" into the severity of their condition or the benefits of medication, or that their disorder hinders their ability to weigh the pros and cons of medication use (3, 7, 8). These assumptions have contributed to the widely held view of non-adherence as a negative phenomenon, as reflected in the identification of treatment adherence by the World Health Organization (WHO) as a topic of top priority in the use of evidence-based medicine (9), consequently encouraging the development of interventions to address this issue (10–12).

Although the negative consequences of non-adherence have long been noted, a growing body of research on the long-term impact of psychiatric medication on various life domains has challenged the simplistic assumption that adherence is necessarily a desired and rational choice (13–15). As such, there has been an increased effort to support people who choose to reduce dosage or stop medication use entirely (16, 17). In addition, the emphasis on personal recovery, self-determination, and shared decision-making (18, 19), along with consumers' first-person accounts (20) and policy developments such as forming medication-free psychiatric wards (21), have generated a shift in focus. This shift could be described as moving from a narrow dichotomous perspective to a wider perspective in which the factors that influence attitudes toward and patterns of psychiatric medication use can be better understood.

A recent systematic review of reasons for non-adherence among people with an SMI revealed that a negative attitude toward medication was the key reason for intentional non-adherence (7). According to the Health Belief Model (22), attitudes toward medication consist of different beliefs including; perceived benefits and barriers of adherence, perceived susceptibility, and perceived severity of outcome. Despite the widely used Drug Attitude Inventory which entails two main clusters – namely, one's subjective experience of medication and one's general beliefs and attitudes about medication (23) – most studies refer to attitudes toward medication in a dichotomous manner (i.e., positive vs. negative). In doing so, the assessment of attitudes toward medication has struggled to capture the complexity of attitudes toward medication and changes over time in the way people weight their impact on various life domains (24, 25). Regarding medication use, qualitative studies have helped us gain a better and deeper understanding of the heterogeneity of people's experiences with psychiatric medication (26–29). These studies have emphasized how people often choose to reduce the dosage or stop medication use entirely for a variety of reasons, including the way the medication was introduced, prescribed, perceived, and the way they evaluated its impact. These studies also revealed that the dichotomous categorizing of adherence as "yes" or "no" is simplistic and ignores the wide range of ways in which people use their medication.

There are several classic explanatory models and conceptual frameworks that have aimed to explain the complexity of medication adherence in mental health (e.g., 30–32). McCan and colleagues (33) offered the Self-Efficacy Model of Medication Adherence (SEMMA) in SMI, a theory-driven model based on a systematic review that refers to adherence and non-adherence as a continuum, instead of a dichotomous construct. In the model, core factors such as self-efficacy, perceived medication efficacy, and relationships with health professionals, as well as contextual influences such as personal issues or side effects as factors which influence the way people use their medications, were identified (33). The model emphasizes the synergistic interaction between the different variables in their total influence on the person's adherence level; however, not being longitudinal, it cannot explain the nature of this complex interaction over time in a person's coping process with an SMI.

As evident from the increased amount of literature on the subject, attitudes toward medication and patterns of use are complex and highly influenced by the individual's experiences, beliefs, relationships, and preferences at a given time. The purpose of the present study was to investigate subjective perceptions of factors that impact attitudes toward and patterns of medication use, and how these two interact over time.

Method

Participants

Research participants were 16 individuals with an average age of 38.5 ($SD = 11.3$). Inclusion criteria included (1) having a diagnosis of an SMI such as schizophrenia/schizoaffective disorder, bipolar disorder, or major depressive disorder (based on the Mini International Neuropsychiatric Interview/MINI structured interview for psychiatric diagnosis); (2) meeting the criteria for having a psychiatric disability severe enough to compromise at least 40% of one's functional ability as determined by a medical committee including a psychiatrist and recognized by National Insurance Institute (NII) regulations, and (3) having used a psychiatric medication at some point in their life for at least one full year after a major psychiatric crisis (anti-psychotic and/or mood stabilizers for bipolar disorder or major depression; *mean* time of medication use = 14.03 years, $SD = 8.25$). Of the 16 participants, four did not take medication at all at the time of the interviews, six took medications as prescribed on a regular basis, and the remaining six reported taking lower doses than prescribed or only at times of crisis (measured by a self-report question, see Instruments). Further sociodemographic and medical background characteristics are presented in Table 1.

Procedure

The study was approved by Bar-Ilan University's Committee for Ethical Research with Humans (#2021/01). Recruitment of participants was carried out over the course of a year at two community mental health centers and *via* website advertisements. Individuals who expressed an interest in participating in the study were first given an explanation about the study by a clinician who was working in the setting where they were receiving treatment, or by the research team if participants were responding to an advertisement. Those who agreed to participate were given detailed information about the study's focus, procedure, and confidentiality issues, and all participants signed a consent form. All participants completed the MINI (34) for the DSM-IV, a short self-report form with some psychosocial and medical background information, and participated in an interview carried out by the first author (M.A). Interviews took place at the two mental health centers or in public places depending on the participants' preferences, and lasted usually an hour. All interviews were recorded and transcribed, the content was kept confidential, and names or any identifying details were changed during the transcribing of the interviews to ensure anonymity. During the process of data collection and data analysis, the issue of adequate sample size needed for reaching saturation was constantly reviewed, based on the "information power" concept for qualitative research (35). In this process we took under consideration sample specificity, ensuring we had a representation of different diagnoses, of diverse patterns of medication use, and of sociodemographic background in our sample. Furthermore, another factor that contributed to the study's information power was the quality of the dialog (35): The interviewer (first author) was a rehabilitation psychologist and PhD student with a background in working with people with SMIs, who was trained and experienced in conducting qualitative interviews.

Instruments

1. The Mini-International Neuropsychiatric Interview/MINI (34) for the DSM-IV was used.
2. Sociodemographic and medical data were collected *via* self-report (see Table 1).
3. Pattern of medication use was assessed *via* self-report of the level of medication adherence on a 5-point scale, as in a previous study (36). This measure was carried out in order to ensure heterogeneity and representation of use patterns.
4. Semi-structured interview: The interview that was conducted derived from the narrative approach, and focuses on the story as the person chooses to tell it (37). Narrative approaches have been found to be especially relevant when assessing experiences of people in mental health recovery (38). First, participants were invited to share their experiences with psychiatric medications, from the moment the medications were first prescribed, and the process they underwent with these medications until the present time. In this part of the interview we aimed to capture participants' unique experiences, thoughts, and feelings, and possible challenges in their process of coping with medication decisions. The second part consisted of specific questions which focused on possible factors that shape people's attitudes and use patterns. Sample questions included: "What are your current beliefs about psychiatric medication?" or "What do you think about deciding to take or not to take medication?"

TABLE 1 Sociodemographic and medical background characteristics of the sample.

Variable	N	%
Gender		
Men	9	56.2
Women	7	43.8
Education		
X < 12	1	6.2
High school	8	50
Higher education (BA, MA, PhD)	7	43.8
Diagnosis		
Schizophrenia	4	25
Schizoaffective	5	31.2
Bipolar disorder	6	37.5
Major depressive disorder	1	6.3
Duration of illness (DOI)		
DOI < 2	1	6.3
2 < DOI < 5	1	6.3
5 < DOI < 10	4	25
DOI > 10	10	62.3
Number of hospitalizations		
X < 2	7	43.7
2 < X < 5	7	43.7
X > 10	2	12.5

N = 16.

Data analysis

Qualitative data were subject to thematic analysis using a narrative methodology, from a realistic point of view (i.e., reporting the meaning, experiences, and reality of the participants; 39). Data were analyzed in Hebrew and then translated into English. Data analysis followed the process of conceptualization including: (1) Reading the interviews several times to become familiar with the data. Data from all interviews were included in the analysis; (2) Interview data were coded for content line-by-line using the ATLAS.ti platform, with the marking of meaningful statements and quotations. This coding process was carried out by two judges (Authors 1 and 2), with Author 2 being masked to any information about the study's participants or to the coding system developed. Furthermore, the order of the coding process between the interviews was different for each judge (i.e., Author 1 analyzed *via* the origin sequence, and Author 2 *via* a randomized order; 40). It can therefore be assumed that the coding and marking of meaningful units represented participants' experiences rather than possible biases of the judges during the coding process; (3) Intercoder agreement analysis was performed, and reliability reached 88.8%. Discrepancies in coding were resolved through discussion until a consensus was reached; (4) All initial codes were classified under categories, for each interview separately. Categories that were the most prevalent and had the richest data were marked and labeled; (5) Categories from all interviews were then organized under main themes and subthemes. Of note, data collection and analysis were also performed simultaneously, until code saturation and meaning saturation were reached and no additional meaningful topics emerged (41); and (6) Building a model from the emerging themes (see Figure 1), which represent the factors that influence attitudes toward and patterns of use at different phases in participants' narratives.

Results

The analysis of the interviews yielded three discrete phases in the process of coping with medication prescription and adherence. Each phase was characterized by different dominant themes reflecting attitudes and patterns of use. Although the phases were sequential, the movement between them was fluid and dynamic, meaning that themes from previous phases could also be influential at later phases, and that changes in people's relationships, illness course, or new experiences with medication could tilt the balance between the interacting themes and change the phase that the person currently occupied. The three phases were conceptualized by participants as: (1) "loss of self" and a high level of medication use; (2) accumulating experiences of using/reducing/

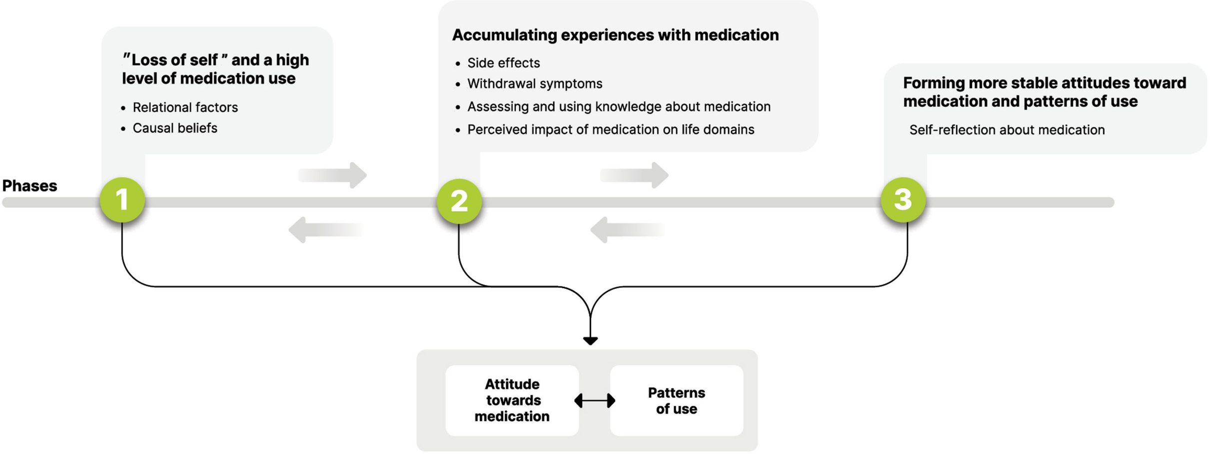

FIGURE 1
Longitudinal model of factors influencing attitudes toward medication and patterns of use.

stopping medication; and (3) forming more stable attitudes toward medication and developing one's own pattern of use.

1. First phase: "Loss of self" and a high level of medication use

This phase refers to the period that came immediately after being diagnosed. During this phase there was no inner dialog about the use of medication but rather simple adherence. During this phase participants described a strong feeling of being engulfed by their illness, and a loss of identity and sense of being. Aviram for example shared:

> If you had spoken with me a year ago, you would have seen that I could barely say a word. I was completely disconnected and had already given up on myself. I felt that my whole identity and inner experience was coffee and cigarettes. I lost my identity, my memory, total emptiness… I took the medication, although I think that at first I objected to taking medication, but then I was disconnected from this for several years.

Two themes emerged, which represent the dominant factors that affected attitudes toward medication and patterns of use during this phase: (1.1) relational factors, and (1.2) causal beliefs about mental illness.

1.1. Relational factors

All 16 of the participants (16 out of 16[1]) indicated the strong influence that their relationships with their prescribing psychiatrist or close family members and friends had on their attitudes toward medication and patterns of use. The nature of the relationship (i.e., both positive and negative aspects) with the psychiatrist was marked as an important factor with a strong effect on participants' attitudes toward and patterns of use during this phase. Some participants marked in their narratives the positive aspects of the therapeutic alliance, such as open communication, receiving information, and emotional support from the psychiatrist. Others mentioned negative aspects including experiences of being criticized and judged, a lack of clarity and information given about the medication and side effects, and feelings of unresolved disagreements regarding desired processes or goals for treatment. These feelings often evoked intense mistrust and caused participants to hide information from their psychiatrists about changes they had made in their patterns of use or led them to reduce their follow-up visits. Aaron for example said that due to a disagreement with his psychiatrist regarding the focus of his treatment, he stopped seeing him on a regular basis and started to make changes in his patterns of use without supervision:

> I wanted to decrease my medication and he [the psychiatrist] said: "The medication is not the issue here, leave that to me, just take them, what does it matter?" He didn't ask me about my well-being or about the quality of my family life; that wasn't the focus for him. He would try convincing me every time [to use medication], so I began to skip appointments and to see him less and less.

Anna said she spent 5 years of her life, after first experiencing symptoms, feeling that she was unseen by the mental health system. This feeling changed during the next phase when she started seeing a new treating psychiatrist with whom she had a much better therapeutic alliance. She described her experience during the first phase as follows:

> I felt unseen, that my treating psychiatrists were changing constantly, that I was not being treated properly. This feeling was present for years… There was no option not to take the medication, it wasn't a question at all! They [the psychiatrists] didn't talk about the meaning of taking medication, about the possible side effects, about other alternatives that might have had fewer side effects for me… So I didn't question it or ask myself if I should take the medication, I didn't engage in any critical thinking at the time.

In addition to mentioning the importance of the relationship with the psychiatrist, participants emphasized the influence of a person close to them – a family member, spouse, or friend – who suggested considering a change in medication use. For example, Sarah described how at first she wasn't aware of the degree to which the medication was having side effects on her, and she did not think about searching for

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[1] All numbers in themes and subthemes refer to the number of participants who mentioned the related subject in their narrative.

alternatives. She described how her significant other took an important role in indicating the necessity for a change in her medication:

> I wasn't myself back then. I would go to the grocery store and forget why I had gone there, I would get on a bus and forget to get off. It was like I wasn't part of this world. My partner noticed this; it was only thanks to her that they [the psychiatrists] changed my medication. She told my psychiatrist [what was happening] and really insisted [on a change in her medication], because I wasn't aware of anything that was going on at the time.

1.2. Causal beliefs about mental illness

Many participants (9 out of 16) presented different causal beliefs about the onset of their symptoms, including trauma, toxic environments, being a highly sensitive person, the use of drugs, or biogenetic causes. Participants' causal beliefs affected their attitudes toward medication in a range of ways. Those who believed biogenetic factors caused their illnesses tended to develop a more positive attitude toward medication use. For example, Gabriel said: "*If it's a case which is chronic, like in my case, then I need the medication. In my case there is a family background; my grandmother and great grandmother also had bipolar disorder.*"

On the other hand, when participants believed there was a psychosocial explanation for their illness, their attitudes toward medication use were more complex. For example, Sharon, who believed her illness was caused by trauma, said:

> I led a normal life for 30 years, and then I underwent a really bad event that was too difficult for my sensitive mind to handle. It doesn't mean that I had been screwed up since birth. The psychiatrists always ask: "Who's screwed up in the family? Its genetics." Why genetics? Why suggest that this is the only explanation? Because you don't have others? It seems a little irresponsible to me.

Although causal beliefs influenced participants' attitudes toward medication, such attitudes were not necessarily reflected in their patterns of use, and adherence remained high during this phase. In sum, participants conceptualized the first phase after the onset of their illness as a period of "loss of self" characterized by strict medication adherence. During this phase they felt disconnected from themselves and from their identities. They shared the feeling that they did not trust their own decisions in general, and in regard to their care and medication specifically, and thus they tended to rely on their psychiatrist or others close to them (such as family and friends) who usually supported adherence during this phase. In addition, their causal beliefs about mental illness – which were also often influenced by their treatment team, family, and friends – was dominant during this phase and shaped their attitudes toward and actual use of medication.

2. Second phase: Accumulating experiences of using/reducing/stopping medication

After the initially high level of medication adherence post-mental-illness-onset, participants described attempts to reduce and/or stop medication use. Themes that emerged during the second phase, and which will be elaborated upon, included: (2.1) experiencing side effects, (2.2) experiencing withdrawal symptoms, (2.3) accessing and using knowledge about mental illness and medication, and (2.4) assessing and weighing the perceived impact of medication on various life domains, including functioning and symptoms, over time.

2.1. Experiencing side effects: was a theme mentioned by most participants (12 out of 16) as a factor that shaped a negative attitude toward medication. Participants mentioned many physical side effects, such as psychomotor retardation or restlessness, weight gain, and extreme tiredness. For example, John shared: "*I had been an athlete previously, and then I gained 30 kilos… I will never forget the moment that I met up with a childhood friend who barely recognized me… It was a wakeup call.*"

Moreover, participants emphasized various emotional side effects, such as the "zombie effect," a feeling that they were "not themselves" because the medication restricted their range of emotion. Lili said:

> The medication doesn't allow you to have your full range of emotional experiences. It keeps you in a more restricted range. It's not like I haven't experienced happiness or sadness with medication, but I feel like it limits my ability to connect to some internal parts of me that I love.

2.2. Experiencing withdrawal symptoms: was a theme noted by nearly half (6 out of 16) of the participants, who said they therefore felt they had become dependent on and/or addicted to the medication. This feeling, concordantly, had a negative influence on their attitude toward medication. Eve, for example, said: "*Nobody tells you how difficult the withdrawal symptoms are… For me the withdrawal symptoms started immediately, it began with dizziness and electric-shock sensations. It's like a junky who needs the drug, the body goes through detox.*"

2.3. Accessing and using knowledge about mental illness and medication: was a theme mentioned by most of the participants (10 out of 16) as empowering them to form their own attitudes toward medication use. Gathering such knowledge was often an active process and shaped complex attitudes about medication stemming from different sources (books, research, exposure to other people's experiences and first-person accounts), and not relying solely on the opinions that were so influential during the first phase, such as those of their psychiatrist, family, or friends. Participants emphasized how this process allowed them to feel a greater sense of self-efficacy, asserting their agency and arriving at a better understanding of and control over their treatment preferences and choices. For example, Tal shared her personal process of gaining knowledge and feeling empowered by it:

> In the beginning I accepted that the illness was an illness for life, and the medication a medication for life… Then I read a lot of articles, did my own research, went to lectures. I think that for many years I gave a lot of authority to what my psychiatrists said, what was written on a piece of paper, and less authority to my personal strengths. Today this balance has changed.

2.4. Perceived impact of medication on life domains

Over time and with the accumulation of subjective experiences and knowledge about medication, conceptions about its impact on different life domains were formed. The growing appreciation of the impact of using or not using medication on key life domains such as family life, work, and severity of symptoms was also a factor that shaped participants' attitudes toward and patterns of medication use.

Family functioning: Most participants (10 out of 16) described the impact of using, and more often stopping the use of medications, on their own behavior, which in turn influenced their interactions and relationships with family members. Gila shared how after the birth of her daughter she stopped taking medication, which led to a relapse for which she was hospitalized. She described how she currently struggles with her desire to stop taking medication and her family members' response to that desire, based on the previous negative experience:

> I think I'm getting closer to reducing my medication, but I'm also being careful about it, not reckless this time. I know it will scare my husband… I think my taking of medication gives him some peace and quiet right now because he is still traumatized from what happened after the birth. When I started to talk again about reducing the meds, my mom panicked at first… So I think that for now it's better to take them [the medication], just to be safe.

Work: Most of the participants (10 out of 16) displayed a range of opinions about the impact of taking medication vs. not taking medication on their work; some viewed it as a protective factor while others felt the opposite. Gabriel shared:

> The thing about using medication for a long time is that you don't always see the benefits of taking it. People are affected by the reward system, and you don't see the reward when you're in remission. Usually, people see the benefits of using medication only after experiencing several hospitalizations, like I did. I believe that waking up in the morning, and being able to function at work, not having to be hospitalized, that's the true reward of using medication.

On the contrary, John felt that taking meds harmed his work performance:

> My life stopped making any forward movement once I started with the meds and I began to be dependent on the status quo: the disability benefits, the social security, living with my parents… I would go to work and fall asleep during my shift. A lot of people were like that due to the medication.

Symptoms: Most of the participants (11 out of 16) reported developing their own opinion regarding the impact of medication use on their symptom severity. Some participants thought the medications were helpful, which provided a compelling reason to take the medications as prescribed. Daniel said:

> The medications are necessary for me in order to maintain an ordinary life; they help me to survive. I don't want to stop because every psychotic episode I had was worse than the one before. Today I have the confidence it won't happen again, thanks to the medication I take.

At the same time participants such as Mona (in the following quote) also presented many questions and uncertainties about the relation between medication use and their symptoms:

> I have tried so many medications, and things still don't seem to be in balance. It's really hard to tell if the medication is helpful or not. Did I just wake up moody? Is it the illness or is it the medication? The psychiatrist always asks me if it helped when we upped the dosage. Was it helpful? I have no idea what really helps and what affects what.

In sum, during the second phase and with the accumulation of experiences with medication, several factors emerged that had a powerful influence on attitudes toward medication and patterns of use. The constant interaction between the subjective experience of side effects and/or withdrawal symptoms, becoming knowledgeable about mental illness and medication, and the perceived impact of medication on different life domains over time generated many fluctuations in attitudes and patterns of use during this phase.

3. Third phase: Forming more stable attitudes toward medication and developing one's own pattern of use

The third phase was characterized by coming to conclusions about the lived experience from the previous phases, resulting in more stable attitudes toward medication and actively choosing one's own personal patterns of use.

Self-reflection about medication: Was a theme mentioned by the vast majority of participants (15 out of 16). Participants emphasized how important and valuable it was to reflect upon their overall experience with medication, evaluate trade-offs, and move toward a resolution that reflected a more stable attitude and pattern of use. When reflecting upon the experiences described in the previous phases, participants appraised what mattered most to them, weighed the pro and cons of using medication, and reflected on personal dilemmas or decisional conflicts that arose. This process generated two main approaches that reflect the resolution of a formed attitude and choosing a pattern of use: medication as a "crutch" and medication as a "cast."

Medication as a "crutch" represents a perception of the long-term use of medication as a protective factor that enhances recovery. This view was found in the current study to be related to a positive attitude toward medication and higher adherence levels. Anna, for example, formed this perception about medication after much trial and error in her patterns of use, due to experiencing side effects as well as several changes in her treating psychiatrists. She shared that currently she feels safer with the support of medication: "*Today I feel that it [the medication] protects me. I think this feeling is meaningful in my recovery process. I think that it keeps me from falling… It feels as if it's like grabbing onto something other than myself.*"

Medication as a "cast" represents a perception of medication as a short-lived and temporary form of support when symptoms begin to intensify. Participants who subscribed to this idea felt that medication use should not be ongoing or long-term because medication harms the recovery process in the long run and in the bigger picture. Udi, who stopped taking medication after having a powerful feeling of "not being himself," and being influenced by things he had read and heard about medication and other treatment options, shared:

> A lot of times taking medication is like putting on a cast. If your arm is broken, you put on a cast to fix it. Then the body goes through its own internal processes, which allows the bones to mend, and then you remove the cast. So medication, too, can also really help in different situations. But if someone's arm is broken, and he continues to wear this cast for the rest of his life, what will happen? His arm will weaken, its strength and muscles will degenerate. In my view, that's analogous to the long-term use of medication.

As mentioned earlier, the movement and transitions between different phases is dynamic, suggesting that the resolution during the third phase is not static or permanent, but rather can be influenced by new experiences, changes in symptom severity, and personal dilemmas that arise.

The movement between phases can be seen in the case of Aaron, a 41-year-old man who was diagnosed with bipolar disorder at the age of 23 and stopped taking medication 3 years prior to this interview. Throughout Aaron's narrative, there is a constant shift between the significant themes that affected his attitudes and patterns of use, which depended on his own desires and the challenges he faced during different phases in his life. He described the first phase after illness onset as chaotic, having a psychotic episode followed by a prolonged depression during which he took his medications regularly. He mentioned that his psychiatrist's opinion had a strong effect on him in terms of convincing him to take the medications:

> The psychiatrist convinced me to continue taking my medication… But I always had some questions and doubts about how useful it was. Was the medication helpful? How could I tell what its impact on me was? I knew that I had been psychotic and then I wasn't anymore. So, I did think the anti-psychotics were helpful. If I stopped taking my medications, would I become psychotic again? And I didn't feel the anti-depressants were helping me because back then was when I had the most severe depressive episode I'd ever had.

During the second phase, Aaron had many fluctuations in his patterns of use including attempts to reduce, stop, and use again. This process was generated by the way he perceived the benefits and costs of using or not using medication for various life domains and what was most important to him at a specific time. For example, he stressed how the medication side effects, but mainly his engagement in peer support groups and exposure to critical attitudes toward medication, generated his own negative attitude toward medication and an attempt to stop use. On the other hand, he emphasized how important it was for him to be a reliable husband and parent:

> When my attempts to stop using medication were irresponsible, my wife was against it. When I was high or down [emotionally], it really harmed her and my family. She was against the idea of stopping the meds when I was high and helped me to regulate use: not to stop use when I was already on the edge.

During the third phase, after he had accumulated a lot of experience with medication usage, his view of "medication as a cast" was formed. He concluded that the continuous use of medication was bad for him, and he started the process of discontinuing, but this time in a gradual manner and with support. In response to the interviewer's question about what had shaped his current attitude, he shared his reflection about medication use as a complex trade-off and having to deal with the conflicts it generates:

> On the one hand, there are the side effects, which make you want to stop or lower the medication dosage. I couldn't remember when I had last cried; you miss your emotions. But there is also a lot of fear, on both sides. I will compare it to my wife's giving birth; she wanted to have a natural birth, mostly because she's scared of hospitals. So what is more scary for her? The risk of a home birth or the fear of giving birth in a hospital? There is so much uncertainty, and this uncertainty might all be based on stories. For example, there were all kinds of stories about my depression, and how I behaved when I took the medication. Because I had episodes of mania and of depression when I took the medication, there were times I cried and others when I didn't. It might also be that stories I internalized from an anti-psychiatric stance influenced me… It's too complex to make generalizations. The truth is more complicated than all of the stories.

Throughout Aaron's narrative, it is clear how his subjective experiences generated his "medication as a cast" attitude and his attempts to withdraw from medication. Although Aaron eventually arrived at a more stable attitude, his narrative indicated several transitions between the second and third phase in both directions. This non-linear movement between phases occurred after new experiences with medication, the course of his illness (which included relapses), and his family life. All of these were significant themes and experiences that shaped his ongoing process of forming attitudes toward medication and developing his own pattern of use.

Discussion

The present study reveals the complex and dynamic process of forming attitudes toward medication and decisional aspects regarding personal patterns of use. Our findings shed light on the process that people with an SMI undergo when psychiatric medication is prescribed for them and they must contend with dilemmas around adherence: from being overwhelmed by the onset of the illness and relying heavily on the treating staff and significant others (leading to high adherence) to taking a more active role in decision-making based on the accumulation of experiences and self-reflection (leading to personal preferences and a more stable attitude toward medication usage). This process progresses through distinct phases as proposed in our model (see Figure 1) and corresponds with Deegan and Drake's (24) statement that compliance or adherence constructs fail to capture the complexity of decisions related to medication use, being active processes that entail many conflicts.

Our model in some ways resembles the Self-Efficacy Model of Medication Adherence (SEMMA), a theory-driven model which views adherence as a continuum, self-efficacy as a core influencing element, and the interaction between different variables (e.g., perceived medication efficacy, personal issues, social stigma) as exerting an overall influence on people's adherence level (33). First, similar factors were found to be influential on patterns of use in both models, such as perceived medication efficacy, relationships with health professionals or significant others, and medication side effects (33). Second, both models refer to adherence as a continuum, what we have termed "patterns of use," reflecting the heterogeneity embedded in the construct of adherence. Nonetheless, two fundamental differences should be noted. Our model expands on SEMMA's placing the person at the heart of the approach by referring to people's attitudes toward medication as a core element in the model in addition to people's actual patterns of use. This distinction is important as it reveals possible complex conflicts within people, when different factors influencing their attitudes and patterns of use tilt the balance and might generate a pattern of use which is quite opposite to people's stated attitude toward medication. This conflict was illustrated in the case study presented, for example when Aaron had a negative attitude toward medication but was adherent because of his wife's opinion and his understanding of how withdrawal could have negative effects on his family. Referring to patterns of use alone would discount the complexity embedded in decisions about medication use, which are highly influenced by people's attitudes (7). The third phase of our model (see Figure 1), which reflects people's thoughts about medication and evaluating the trade-offs of use vs. non-use, represents this complexity within people's decision-making processes. Extending the focus from factors influencing adherence to understanding people's attitudes, beliefs, and values regarding medication use can also help to promote shared decision-making, a process wherein clinicians and patients work together, recognizing and respecting patients' preferences and role in managing their health (42).

The second way in which our model differs from current and classic models for understanding adherence among individuals with an SMI (e.g., 30, 32, 33, 43), and with utmost significance, is that it emphasizes longitudinal aspects and dynamic processes: namely, in each phase different themes interact with each other and exert a greater influence on people's decision-making processes. The model indicates that there is no single element that is more influential than another in its total effect on attitudes and usage patterns; rather, one element may be more dominant than another at a given timepoint, depending on the individual's personal evaluation of its significance. Although the model emphasizes distinctive sequential phases, it also represents a non-linear process where the movement between phases is dynamic, and different experiences (i.e., relapses, changes in the family status, occupation, gaining new knowledge about medication) can create movement back to previous stages.

Reframing medication decision-making as a dynamic, non-linear process is a potentially important conceptual development with several implications. First, such reframing is in line with other prominent and influential frameworks that have emphasized mental health recovery as a non-linear dynamic process (19, 44–46). Second, this model aligns with other models that indicate discrete phases in recovery processes (e.g., 47–49). Davidson and colleagues (47) offered a model that outlined stages of change in mental health recovery but emphasized the limited nature of this model, as it excludes the non-linear nature of recovery. They identified five distinct stages, a few of which correspond with the current model of forming attitudes toward medication and patterns of use (see Figure 2). The first stage, termed "pre-contemplation" or "pre-recovery," is characterized by feelings of powerlessness, confusion, despair, and a feeling that the self is overwhelmed by and immersed in the disorder. This stage mirrors the first stage in the present model: the "loss of self" and high levels of medication use. Identifying this distinctive phase in the process of forming attitudes toward and patterns of medication use is critical, as it emphasizes the time period after illness onset, when the patient might be overwhelmed with new experiences, and decisional processes seem to require the involvement of others (formal or informal). This notion was expressed by participants in the current study, sharing their limited ability to make decisions during this phase and their need for assistance from psychiatrists, family, and friends.

The next two phases in the "stages" model of change in recovery (47) – "contemplation," which is the growing awareness of a desirable behavioral change, and "preparation," which is planning for a change and a transformation of the self from passive to active – resemble the second stage of our model: "accumulating experience of using/reducing/stopping medication." This transition from passive to active can be seen for example in the transformation from causal beliefs, a relatively passive process of attribution for the illness cause (50) during the first stage, to an active search for knowledge and understanding, as seen in the second phase. This transformation to having an active role was marked by participants as empowering in their process of forming attitudes toward medication and choosing one's own pattern of use.

Last, the "action" phase in recovery processes (47) reflects an intentional effort to cope with the illness and work on personal goals. This phase is reflected in our final phase, when the person forms an integrated and stable attitude toward medication use, representing their personal preferences about treatment and values and putting them into action when choosing their pattern of use. It is not surprising that there are parallel processes and many similarities between recovery stages, and the process of coping with medication prescription and adherence decisions, when forming personal attitudes toward medication. Being able to reflect upon treatment preferences and options, having choices, and taking control of one's life are fundamental aspects of recovery in mental health.

Limitations

The current study had several limitations. First, although the sample size was adequate, it was nevertheless relatively small; as such, generalizing from the results should be done cautiously. Furthermore, it is possible that due to the small sample size, significant themes that have been found in the literature as being influential on people's patterns of

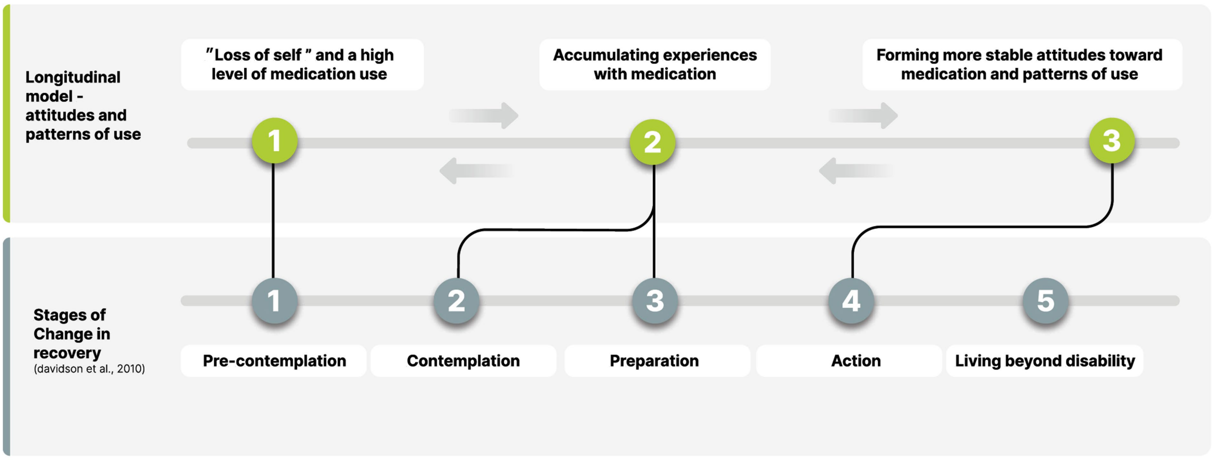

FIGURE 2
Comparison to stages of change in recovery model.

use (e.g., perceived stigma; substance abuse; 3, 7) were not sufficiently represented in the current data set. Second, the study applied a retrospective design, in which participants were asked to share their experiences with medication from illness onset until the present; recall bias thus undoubtedly exerted an influence, especially as many of the study participants had long duration of illness. Third, as recruitment was carried out in different settings simultaneously, and during the COVID-19 pandemic, the interviews took place in different settings (see Procedure) which might have influenced participants' ability to openly share difficult issues in their personal narratives.

Implications for theory, research, and practice

The proposed longitudinal model of factors influencing attitudes toward medication and patterns of use emphasizes the different challenges in the complex process of forming such attitudes and choosing patterns of use. The model comprises three distinctive phases of attitude formation and consequent pattern of use over the course of many years and decades of coping with an SMI. Several implications of the model should be considered. First, the growing understanding that adherence is not a dichotomous construct but rather a continuum (33) with different patterns of use is crucial for theory and practice. There is a wide range of ways in which people choose to use their psychiatric medication, and these ways are subject to change over time. In addition, we must aim to change the perception of non-adherence as being necessarily a negative phenomenon; rather, it should be accepted as a treatment preference and a legitimate life choice (51). Second, clinicians should be encouraged to try to identify the phase their patients currently occupy in the process of forming attitudes toward medication and choosing patterns of use. Identifying the phase will enable clinicians to better understand possible challenges and related themes that affect their patients' attitudes and patterns of use and establish a joint reflective dialog to enhance alliance and shared decision-making. Finally, broader, more flexible, and nonlinear models of the process of forming attitudes toward medication and choosing patterns of use are needed to deepen our understanding of the changes and difficult issues that arise when coping with medication prescription and adherence decisions.

Going forward, researchers should aim to develop tools that refer to and measure patterns of use and attitudes toward medications as complex concepts. We should also adapt qualitative measures for measuring adherence and take into consideration the personal significance of different factors that influence people's attitudes toward medication. Models should refine and try to accurately assess the complex interaction between factors influencing attitudes toward medication and patterns of use, with a longitudinal design and with heterogeneity in participants' duration of illness, as different phases in coping with an SMI and medication use raise different challenges and dilemmas over time.

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 Bar-Ilan University's Committee for Ethical Research with Humans (#2021/01). The patients/participants provided their written informed consent to participate in this study.

Author contributions

MA interviewed all the participants and wrote the first draft of the manuscript. MA and DR analyzed the qualitative data. DR and IH-O contributed in editing and revising the manuscript. All authors took part in conceptualizing the ideas and planning the research procedure.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders: DSM-5. 2013.* Washington, DC: American Psychiatric Association (2013).
2. National Institute for Health and Clinical Excellence (Great Britain). *Psychosis and Schizophrenia in Adults: Treatment and Management*. London: National Institute for Health and Care Excellence (UK). (2014).
3. Semahegn, A, Torpey, K, Manu, A, Assefa, N, Tesfaye, G, and Ankomah, A. Psychotropic medication non-adherence and its associated factors among patients with major psychiatric disorders: a systematic review and meta-analysis. *Syst Rev.* (2020) 9:1–8. doi: 10.1186/s13643-020-1274-3
4. Higashi, K, Medic, G, Littlewood, KJ, Diez, T, Granström, O, and De Hert, M. Medication adherence in schizophrenia: factors influencing adherence and consequences of nonadherence, a systematic literature review. *Ther Adv Psychopharmacol.* (2013) 3:200–18. doi: 10.1177/2045125312474019
5. Stentzel, U, van den Berg, N, Schulze, LN, Schwaneberg, T, Radicke, F, Langosch, JM, et al. Predictors of medication adherence among patients with severe psychiatric

disorders: findings from the baseline assessment of a randomized controlled trial (Tecla). *BMC Psychiatry*. (2018) 18:1–8. doi: 10.1186/s12888-018-1737-4

6. Subotnik, KL, Nuechterlein, KH, Ventura, J, Gitlin, MJ, Marder, S, Mintz, J, et al. Risperidone nonadherence and return of positive symptoms in the early course of schizophrenia. *Am J Psychiatr*. (2011) 168:286–92. doi: 10.1176/appi.ajp.2010.09010087
7. Velligan, DI, Sajatovic, M, Hatch, A, Kramata, P, and Docherty, JP. Why do psychiatric patients stop antipsychotic medication? A systematic review of reasons for nonadherence to medication in patients with serious mental illness. *Patient Prefer Adherence*. (2017) 11:449–68. doi: 10.2147/PPA.S124658
8. Novick, D, Montgomery, W, Treuer, T, Aguado, J, Kraemer, S, and Haro, JM. Relationship of insight with medication adherence and the impact on outcomes in patients with schizophrenia and bipolar disorder: results from a 1-year European outpatient observational study. *BMC Psychiatry*. (2015) 15:1–8 doi: 10.1186/s12888-015-0560-4.
9. World Health Organization. *Adherence to Long-Term Therapies: Evidence for Action*. Geneva: World Health Organization (2003).
10. Schulze, LN, Stentzel, U, Leipert, J, Schulte, J, Langosch, J, Freyberger, HJ, et al. Improving medication adherence with telemedicine for adults with severe mental illness. *Psychiatr Serv*. (2019) 70:225–8. doi: 10.1176/appi.ps.201800286
11. Tessier, A, Dupuy, M, Baylé, FJ, Herse, C, Lange, AC, Vrijens, B, et al. Brief interventions for improving adherence in schizophrenia: a pilot study using electronic medication event monitoring. *Psychiatry Res*. (2020) 1:112780. doi: 10.1016/j.psychres.2020.11278
12. Zygmunt, A, Olfson, M, Boyer, CA, and Mechanic, D. Interventions to improve medication adherence in schizophrenia. *Am J Psychiatr*. (2002) 159:1653–64. doi: 10.1176/appi.ajp.159.10.1653
13. Almohammed, OA, Alsalem, AA, Almangour, AA, Alotaibi, LH, Al Yami, MS, and Lai, L. Antidepressants and health-related quality of life (HRQoL) for patients with depression: analysis of the medical expenditure panel survey from the United States. *PLoS One*. (2022) 17:e0265928. doi: 10.1371/journal.pone.0265928
14. Wunderink, L, Nieboer, RM, Wiersma, D, Sytema, S, and Nienhuis, FJ. Recovery in remitted first-episode psychosis at 7 years of follow-up of an early dose reduction/discontinuation or maintenance treatment strategy: long-term follow-up of a 2-year randomized clinical trial. *JAMA Psychiat*. (2013) 70:913–20. doi: 10.1001/jamapsychiatry.2013.19
15. Moncrieff, J. Antipsychotic maintenance treatment: time to rethink? *PLoS Med*. (2015) 12:e1001861. doi: 10.1371/journal.pmed.1001861
16. Miller, R, and Pavlo, AJ. Two experts, one goal: collaborative deprescribing in psychiatry. *Curr Psychiatr Rev*. (2018) 14:12–8. doi: 10.2174/1573400514666180531095618
17. Standal, K, Solbakken, OA, Rugkåsa, J, Martinsen, AR, Halvorsen, MS, Abbass, A, et al. Why service users choose medication-free psychiatric treatment: a mixed-method study of user accounts. *Patient Prefer Adherence*. (2021) 15:1647–60. doi: 10.2147/PPA.S308151
18. Drake, RE, Deegan, PE, and Rapp, C. The promise of shared decision making in mental health. *Psychiatr Rehabil J*. (2010) 34:7–13. doi: 10.2975/34.1.2010.7.13
19. Slade, M. *Personal Recovery and Mental Illness: A Guide for Mental Health Professionals*. Cambridge: Cambridge University Press (2009).
20. Gumber, S, and Stein, CH. Consumer perspectives and mental health reform movements in the United States: 30 years of first-person accounts. *Psychiatr Rehabil J*. (2013) 36:187–94. doi: 10.1037/prj0000003
21. Yeisen, RA, Bjørnestad, J, Joa, I, Johannessen, JO, and Opjordsmoen, S. Psychiatrists' reflections on a medication-free program for patients with psychosis. *J Psychopharmacol*. (2019) 33:459–65. doi: 10.1177/0269881118822048
22. Carpenter, CJ. A meta-analysis of the effectiveness of health belief model variables in predicting behavior. *Health Commun*. (2010) 25:661–9. doi: 10.1080/10410236.2010.521906
23. Hogan, TP, Awad, AG, and Eastwood, R. A self-report scale predictive of drug compliance in schizophrenics: reliability and discriminative validity. *Psychol Med*. (1983) 13:177–83. doi: 10.1017/S0033291700050182
24. Deegan, PE, and Drake, RE. Shared decision making and medication management in the recovery process. *Psychiatr Serv*. (2006) 57:1636–9. doi: 10.1176/ps.2006.57.11.1636
25. Zisman-Ilani, Y, Shern, D, Deegan, P, Kreyenbuhl, J, Dixon, L, Drake, R, et al. Continue, adjust, or stop antipsychotic medication: developing and user testing an encounter decision aid for people with first-episode and long-term psychosis. *BMC Psychiatry*. (2018) 18:142. doi: 10.1186/s12888-018-1707-x
26. Geyt, GL, Awenat, Y, Tai, S, and Haddock, G. Personal accounts of discontinuing neuroleptic medication for psychosis. *Qual Health Res*. (2017) 27:559–72. doi: 10.1177/1049732316634047
27. Katz, S, Goldblatt, H, Hasson-Ohayon, I, and Roe, D. Retrospective accounts of the process of using and discontinuing psychiatric medication. *Qual Health Res*. (2019) 29:198–210. doi: 10.1177/1049732318793418
28. Salomon, C, and Hamilton, B. "All roads lead to medication?" Qualitative responses from an Australian first-person survey of antipsychotic discontinuation. *Psychiatr Rehabil J*. (2013) 36:160–5. doi: 10.1037/prj0000001
29. Swarbrick, M, and Roe, D. Experiences and motives relative to psychiatric medication choice. *Psychiatr Rehabil J*. (2011) 35:45–50. doi: 10.2975/35.1.2011.45.50
30. Ajzen, I. *From Intentions to Actions: A Theory of Planned Behavior. In Action Control*. (pp. 11–39). Springer: Berlin, Heidelberg. (1985).
31. Leventhal, H, and Cameron, L. Behavioral theories and the problem of compliance. *Patient Educ Couns*. (1987) 10:117–38. doi: 10.1016/0738-3991(87)90093-0
32. Rosenstock, IM. Historical origins of the health belief model. *Health Educ Monogr*. (1974) 2:328–35. doi: 10.1177/109019817400200403
33. McCann, TV, Clark, E, and Lu, S. The self-efficacy model of medication adherence in chronic mental illness. *J Clin Nurs*. (2008) 17:329–40. doi: 10.1111/j.1365-2702.2008.02354.x
34. Sheehan, DV, Lecrubier, Y, Sheehan, KH, Amorim, P, Janavs, J, Weiller, E, et al. The MINI-International Neuropsychiatric Interview (MINI): the development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. *J Clin Psychiatry*. (1998) 59:22–33.
35. Malterud, K, Siersma, VD, and Guassora, AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res*. (2016) 26:1753–60. doi: 10.1177/1049732315617444
36. Moritz, S, Favrod, J, Andreou, C, Morrison, AP, Bohn, F, Veckenstedt, R, et al. Beyond the usual suspects: positive attitudes towards positive symptoms is associated with medication noncompliance in psychosis. *Schizophr Bull*. (2013) 39:917–22. doi: 10.1093/schbul/sbs005
37. Josselson, R. *Interviewing for Qualitative Inquiry: A Relational Approach*. New York: Guilford Press (2013).
38. Spector-Mersel, G, and Knaifel, E. Narrative research on mental health recovery: two sister paradigms. *J Ment Health*. (2018) 27:298–306. doi: 10.1080/09638237.2017.1340607
39. Clarke, V, Braun, V, and Hayfield, N. Thematic Analysis In: JA Smith, editor. *Qualitative Psychology: A Practical Guide to Research Methods*. London: SAGE Publications (2015)
40. Hennink, MM, Kaiser, BN, and Weber, MB. What influences saturation? Estimating sample sizes in focus group research. *Qual Health Res*. (2019) 29:1483–96. doi: 10.1177/1049732318821692
41. Hennink, MM, Kaiser, BN, and Marconi, VC. Code saturation versus meaning saturation: how many interviews are enough? *Qual Health Res*. (2017) 27:591–608. doi: 10.1177/1049732316665344
42. Coulter, A, and Collins, A. *Making Shared Decision-Making a Reality*. London: King's Fund (2011).
43. Moitra, E, and Gaudiano, BA. A psychological flexibility model of medication adherence in psychotic-spectrum disorders. *J Contextual Behav Sci*. (2016) 5:252–7. doi: 10.1016/j.jcbs.2016.10.003
44. Davidson, L, and Roe, D. Recovery from versus recovery in serious mental illness: one strategy for lessening confusion plaguing recovery. *J Ment Health*. (2007) 16:459–70. doi: 10.1080/09638230701482394
45. Leonhardt, BL, Hamm, JA, and Lysaker, PH. The recovery model and psychosis In: JC Badcock and G Paulik, editors. *A Clinical Introduction to Psychosis: Foundations for Clinical Psychologists and Neuropsychologists*. Cambridge, MA: Elsevier (2020)
46. Van Weeghel, J, van Zelst, C, Boertien, D, and Hasson-Ohayon, I. Conceptualizations, assessments, and implications of personal recovery in mental illness: a scoping review of systematic reviews and meta-analyses. *Psychiatr Rehabil J*. (2019) 42:169–81. doi: 10.1037/prj0000356
47. Davidson, L, Roe, D, Andres-Hyman, R, and Ridgway, P. Applying stages of change models to recovery from serious mental illness: contributions and limitations. *Isr J Psychiatry Relat Sci*. (2010) 47:213–21. PMID: 21149986
48. Strauss, JS, Hafez, H, Lieberman, P, and Harding, CM. The course of psychiatric disorder: III. Longitudinal principles. *Am J Psychiatry*. (1985) 142:289–96.
49. Yarborough, BJ, Yarborough, MT, Janoff, SL, and Green, CA. Getting by, getting back, and getting on: matching mental health services to consumers' recovery goals. *Psychiatr Rehabil J*. (2016) 39:97–104. doi: 10.1037/prj0000160
50. Carter, L, Read, J, Pyle, M, and Morrison, AP. The impact of causal explanations on outcome in people experiencing psychosis: a systematic review. *Clin Psychol Psychother*. (2017) 24:332–47. doi: 10.1002/cpp.2002
51. Roe, D, Hasson-Ohayon, I, and Gornemann, MI. Reasons for discontinuing attendance at a group intervention among people with serious mental illness. *Psychiatr Serv*. (2016) 67:1043. doi: 10.1176/appi.ps.201600172

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Validation of the Malay-Version of Recovery Knowledge Inventory among mental health providers in Malaysia

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Background: The Recovery Knowledge Inventory (RKI) is a widely used self-report instrument that assesses recovery-oriented knowledge among mental health professionals. The purpose of this study is to translate the RKI into the Malay language (RKI-M) and to examine its psychometric properties among Malaysian health care workers.

Methods: A cross-sectional study involving 143 participants was conducted at an urban teaching hospital, an urban government hospital, and a rural government hospital. Following the translation of the RKI, its internal reliability was determined using Cronbach's alpha. Construct validity was also determined using confirmatory factor analysis.

Results: The Malay-Version RKI (RKI-M) has good internal reliability with a Cronbach's alpha of 0.83. However, the Malay-version RKI failed to replicate the original four-factor structure. The final model only achieved the best model fit after the removal of 9 items with two-factor loadings: (GFI=0.92; AGFI=0 0.87; CFI=0.91; RMSEA=0.074).

Conclusion: The 20-item RKI-M is reliable but has poor construct validity. However, the modified 11-item Malay-version RKI is a more reliable measure as it has good construct validity, with room for future studies to examine the psychometric properties of the modified 11-item RKI among mental health care workers. More training on recovery knowledge should be done, and a simple worded questionnaire should be developed in keeping with local practitioners.

KEYWORDS

Malaysia, validation, confirmatory factor analysis, Recovery Knowledge Inventory, recovery scale

1. Introduction

Recovery in mental illness is an evolving concept that has come a long way since the 1990s. The process of changing one's attitudes, values, feelings, goals, abilities, and roles during recovery is deeply personal and it's a way to manage mental illness while still leading a happy, purposeful life (1). Currently, an increasing number of comprehensive frameworks have attempted to secure the various components of personal recovery (2, 3). One of the most well-known attempts to successfully integrate the numerous recovery constructs already in existence is the CHIME framework. The acronym "CHIME" stands for the model's five recovery processes (3) (i.e., connectedness, hope, identity, meaningfulness, and empowerment). The "C" stands for connectedness, and while less obviously individualistic than Anthony's (1) framework definition, it still exhibits many of the same traits as earlier conceptions of recovery.

Measuring knowledge of recovery is vital in ensuring practices are in keeping with the current understanding of the recovery-oriented approach. It is essential that a valid and reliable tool be in place to evaluate mental health workers' recovery knowledge. Such a tool should be able to gauge the level of knowledge and help improve psychiatric services. The Recovery Knowledge Inventory (RKI) was developed by Bedregal et al. (4) to assess the knowledge on mental health illness and the recovery approach among mental health staff. RKI seeks information on roles and responsibilities in recovery (4). It is used to understand the nonlinear process and roles of self-definitions in recovery and the expectation of recovery (2). The English-version RKI has 20 items and a four-factor structure based on the following four items: (i) roles and responsibilities in recovery, (ii) non-linearity of the recovery process, (iii) roles of self-definition and peers in recovery, and (iv) expectations about recovery. The Cronbach's α coefficients for each domain were 0.81, 0.70, 0.63, and 0.47 (4). The Higher scores indicate more knowledge and positive attitudes toward concept of Recovery (4).

In recent times, research on recovery has often been qualitative rather than empirical. Recovery is usually labeled as a non-linear journey that can be affected by multifaceted factors. The importance of hope and optimism, respecting the knowledge of the service user, valuing diversity, and allowing for risk-taking behaviors are common themes for service delivery that replicate the ideologies of the recovery movement (5). However, for mental health professionals to use this treatment ideology, a deeper comprehension of the ideas of attitude change and recovery is necessary (6).

Malaysia, as a developing nation, is made up of a multi-cultural and multi-lingual community, so it is paramount to develop a validated tool that measures the knowledge of recovery in its national language, Bahasa Malaysia, which is widely used in the country and can be easily understood. This research provides a significant chance to advance our understanding of the recovery approach. At the time of literature review, there were no specific study on recovery-based knowledge and the extent of it being part of the local practices. This study was done to first have a validated objective tool to understand how far our local mental health professionals have a grasp on this model. It is believed that most psychiatrists in Malaysia currently limit their practises to functional and symptom relief and, at times, have some recovery-based practises without realizing it. Furthermore, by using a validated tool objectively, such an effort will be instrumental in shaping the future of mental health services in Malaysia. We predict that the Bahasa Malaysia (RKI-M) will have a satisfactory factorial validity and reliability. It is important to translate and validate the RKI to Bahasa Malaysia to encourage more studies, not only among mental health workers but also among allied health. This study was done with two questions in mind: (i) What is the internal consistency of the RKI-M in a sample of Malaysian Mental Health care workers? and (ii) Will the RKI be able to establish construct validity with the Malay Version of the Recovery Knowledge Inventory in a sample of Malaysian mental health care workers? The main objective of this study is to translate the RKI into Bahasa Malaysia and to examine the psychometric properties of the RKI-M.

2. Methods

2.1. Study design

A cross-sectional study was conducted in the Psychiatry department of three different hospitals, specifically Hospital Canselor Tuanku Muhriz (HCTM), Hospital Tuanku Jaafar Seremban (HTJS), and Hospital Tuanku Ampuan Najihah (HTAN) Kuala Pilah in March 2021. Permission from both the UKM Ethics committee and from the Director-General of Health Malaysia were obtained prior to publication (NMRR-20-301257,590).

HCTM, a teaching center in a university setting, was chosen together with HTJS, a tertiary hospital under the administration of Ministry of Health Malaysia. Both centers are in an urban setting and have both inpatient and community care services. HTAN, which is situated in the rural area of Negeri Sembilan, despite not having a ward setting, has a dedicated team of community mental health care. Purposive sampling was used to include health care workers from rural, urban, and teaching hospitals to obtain a more heterogeneous sample population.

2.2. Development of the Malay Version RKI (RKI-M)

The Recovery Knowledge Inventory has 20 questions comprising four scales: (I) Roles and Responsibilities, (II) Non-Linearity of the Recovery Process, (III) Roles of Self-definition and Peers, and (IV) Expectations Regarding Recovery. This tool uses a 5-point Likert-type scale, which are 1 (Strongly disagree), 2 (Disagree), 3 (Not sure), 4 (Agree), and 5 (Strongly agree). Higher scores indicate having greater knowledge and a more positive attitude toward the concept of recovery. Fifteen items were scored inversely to minimize the influence of social desirability (4). The RKI was translated into the Malay language following permission from the original developer. The translation was based on guidelines for translating and adapting psychometric scales by Gudmundsson (7). First, the English version RKI was translated into Malay independently by two bilingual authors, a psychiatrist, and a linguist. Both translations were then compared and combined to become the Malay-version RKI (8). Then, a different pair of translators (a linguist and a psychiatrist), also bilingual, back-translated the Malay version of RKI-M independently. The translators were first briefed on the target population of the questionnaires. Following this step, the researchers cross-checked the back translation with the original questionnaire. Editing and revision of the translated version were then done to ensure literal and conceptual equivalence between the original RKI and the Malay-version RKI. Next, a pilot study was conducted on 30 participants comprising medical students and house officers currently in their psychiatric rotation (9–11). The participants were enquired about their ease in understanding the questionnaire, and their comments were used to make changes to the RKI-M.

2.3. Participants

One hundred and forty-three participants were recruited through purposive sampling from the three hospitals mentioned above. In keeping with the standard practice applied for factor analysis when the given number of items is 20, as a rule of thumb, a minimum of 5–10 samples is needed per item, which computes to 100 minima to 200 maximum samples (12). In estimating 20% of the non-response rate being ($100 \times 0.2 = 20/200 \times 0.2 = 40$), the total sample required will thus be 120–240. For the Confirmatory Factor Analysis (CFA), more than 3 items per construct plus 0.45–0.55 communality was used (13). The inclusion criteria included all mental health service providers such as registered staff nurses, medical assistants, occupational therapists, psychologists, psychiatrists, and medical officers who have been serving in the psychiatry department for more than 1 year. The exclusion criteria were non-mental health workers such as clerks, hospital attendants, and incomplete questionnaires.

2.4. Procedure

Data collection was carried out both onsite and online during the COVID-19 pandemic in March 2021. The study information sheet that had the objective, the purpose, the inclusion, exclusion criteria along with the consent. The translated version of the RKI-M questionnaire was distributed to all mental health care workers at the said hospitals. In view of the social distancing practices, participants were given the option to fill up an online Google or a hardcopy form. The same questions as the hardcopy were used and the Google Forms link was disseminated *via* the Department's social media platform. The link was also displayed and shared during all Department's teachings and meetings. Participants were reminded to only choose one mode of answering the questionnaire to avoid double sampling. The participants had to give their consent before they could proceed further. A physical drop box was provided at a designated place for the manual forms to be recollected. All participants were kept anonymous as no email or identification numbers were obtained.

2.5. Data analysis

Using SPSS software, all statistical analyses were performed. AMOS software was used for CFA. Given that the original study had performed an Exploratory Factor Analysis (EFA), following a series of discussion, the authors decided that a Confirmatory Factor Analysis (CFA) would be more beneficial to test the fitness of the data for this study (14). The study was conducted using the estimation procedure called Maximum Likelihood Confirmatory Factorial Analysis (15). The factor structure of RKI-M was tested using CFA against the four factors identified by the authors of the original RKI (4). The following fit indices were used for evaluating the model fit: (1) the goodness-of-fit index ($GFI > 0.90$); (2) the adjusted goodness-of-fit index ($AGFI > 0.80$); (3) the Comparative fit index ($CFI > 0.90$); (4) the root mean square error of approximation ($RMSEA < 0.08$); and (5) CMIN/df (<5.0 usually indicates a good fit) (16–18). It is considered acceptable if the factor loading is >0.30. Anything less than this value would imply a poor relationship between the variables (19). Internal consistency was measured using Cronbach's alpha, where a value of 0.7 or more is considered acceptable (20). For the structural equation model, a value of $p < 0.5$ is considered statistically significant (21) (Figures 1–3).

3. Results

3.1. Characteristics of participants

We obtained a total of 143 questionnaires for analysis. A total of 97 participants were from HCTM but only 58 completed the questionnaire (a 60% response rate). From the HTJS tertiary hospital, a total of 95 participants were eligible but only 65 responded (a 68% response rate). HTAN, a rural hospital, had 20 eligible participants and all of them responded (a 100% response rate). The participants' sociodemographic and occupational characteristics are shown in Table 1. Most of the participants were female, and the mean age was 36 years (±6.75). The mean length of experience in Psychiatric services was 11 years (±6.15). The largest occupational group was nurses, comprising about a quarter of the respondents, followed by medical officers. Ethnically, the majority were Malay (75%), followed by Indian (11.9%), and Chinese (8.4%).

Table 2 shows the total mean score between the three different hospitals based on the 11-item RKI-M. HCTM scored a lower mean compared to HTJS while HTAN scored higher, indicating that the latter two hospitals had lesser knowledge of recovery, as their answers were not in keeping with the tenets of the recovery approach. This result could be explained by the fact that HCTM is more academic and has a responsibility to disseminate recent evidence and knowledge. Almost all the staff, doctors, and allied mental health workers in HCTM have had specific training or were currently being trained in psychiatry. The other two Kementerian Kesihatan Malaysia (KKM) hospitals are more service-oriented and are not purely engaged in psychiatry academia and may consist of more lay personnel who might be more heterogenous in knowledge and experience in psychiatry. This data showed that the urban or rural areas did not really matter as much as the setting of the hospital.

3.2. Reliability of RKI-M

The Cronbach's alpha coefficient for the 20-item RKI-M was 0.821. After the removal of the 9 items mentioned earlier, the Cronbach's alpha coefficient became 0. 803. Factor 1 was 0.758, Factor 2 was 0.725, and Factor 3 was 0.533. Factor 3 had poor internal consistency and was not reliable. The other factors had acceptable internal consistency and were reliable.

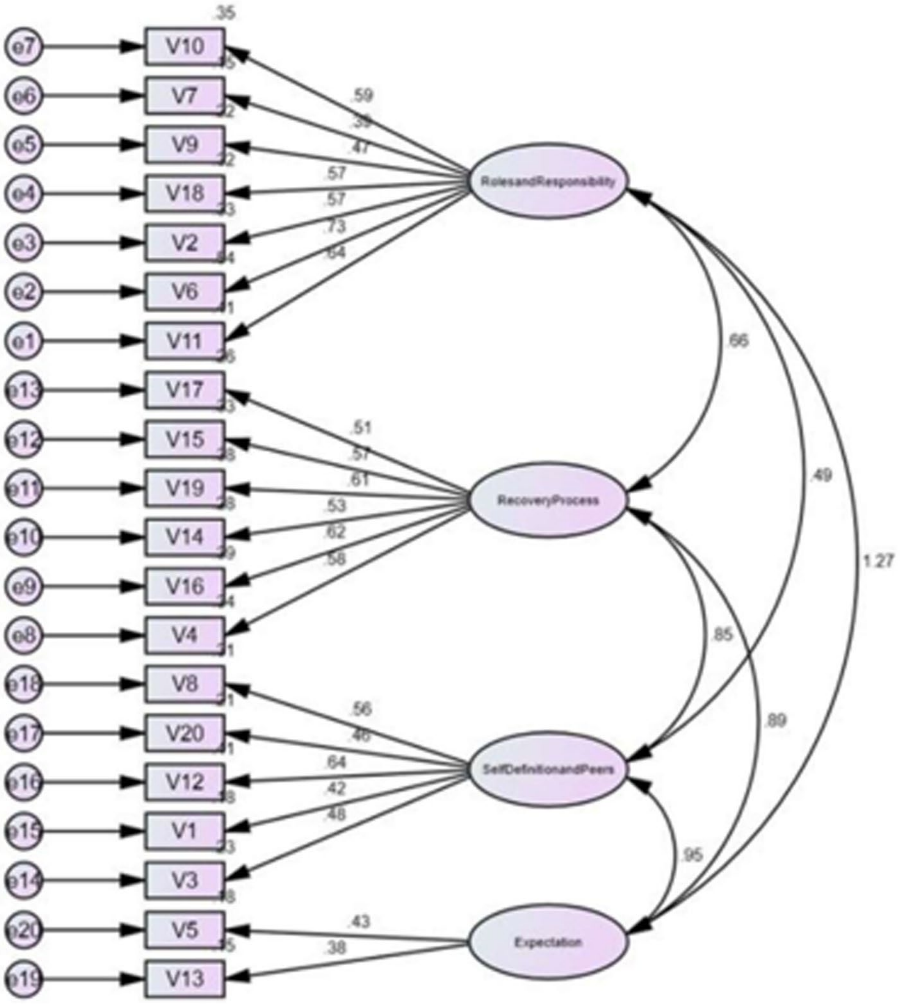

FIGURE 1
Confirmatory factor analysis of four factors.

3.3. Validity of RKI-M

3.3.1. Confirmatory factorial analysis

The mean total of the 20-item RKI score was 76.1 (SD = 18.0; range: 28–100) (Table 3). Based on the original study by Bedregal et al. (4), we matched the items from RKI-M with the original RKI. The 20-item RKI-M did not yield satisfactory results with GFI = 0.82; AGFI = 0.77; CFI = 0.79; RMSEA = 0.082 (Table 4). We initially removed 7 items based on items with a factor loading of less than 0.3–0.4. Factors were reduced to 3. Because of the poor reliability of Factor 3, we proceeded to reduce the number of factors to 2. Hence, we removed a total of 9 items. The deleted items were items 1, 3, 5, 7, 8, 9, 12, 13, and 20. The two factors retained were roles and responsibilities in recovery (Factor 1) and the non-linearity of the recovery process (Factor 2). CFA based on the two-factor structure suggested a good fit to the data and satisfied three out of the four criteria needed to reach the recommended standards (GFI = 0.92; AGFI = 0 0.87; CFI = 0.91; RMSEA = 0.074; Table 5). Table 6 shows the mean comparison based on the different types of occupation. The data shows differences in the mean total for RKI-M in between all types of occupation. A one-way ANOVA revealed that there was a statistically significant difference in mean RKI score between groups ($F(3, 139) = 12.762$, $p < 0.01$). Nurses and medical assistants appear to have better recovery knowledge compared to psychiatrists and medical officers who scored on the lower side.

4. Discussion

The purpose of this study was to validate the Malay version of the RKI and translate it. This study demonstrated that the 20-item RKI-M did not exhibit good construct validity among Malaysian mental health care workers. However, a good fit was achieved when 9 items were removed, producing 2 factors based on 11 items. This was not surprising, as the authors of the original study found that during the development of the RKI, the data collected was preliminary. Moreover, there were several flaws in that study, which may explain the failure of

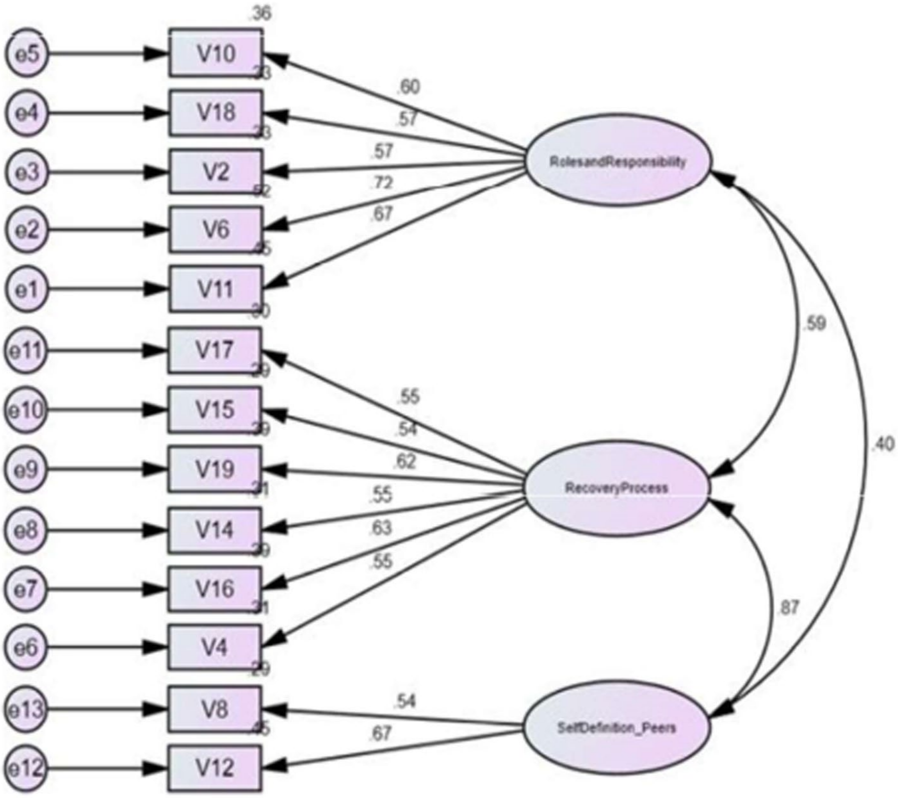

FIGURE 2
Confirmatory factor analysis of three factors.

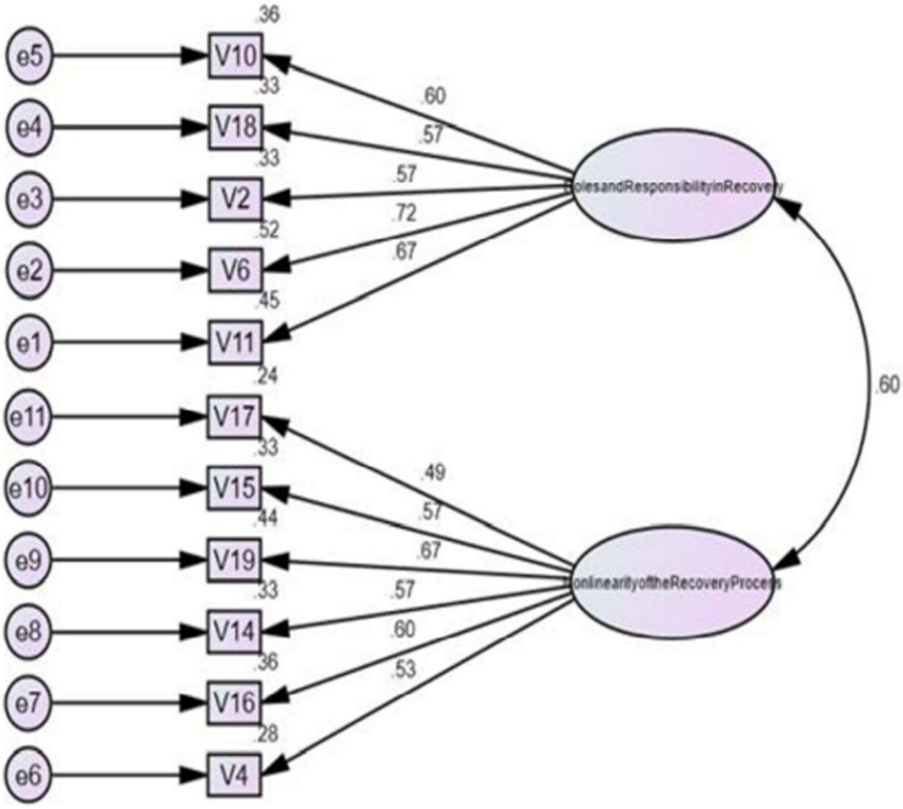

FIGURE 3
Confirmatory factor analysis of two factors.

our study to replicate the RKI entirely (4). The absence of confirmatory results is also supported by other studies' lack of conclusive findings for the factor structure (21–23). Earlier studies in the United States and Norway showed improved construct validity when items with low Cronbach's alpha values of <0.3 were removed. Subsequently, the best fit was found to be 1 factor loading of 10 items (24, 25). A study based on an Asian sample indicated acceptable reliability with 3 factors comprising 16 items (21). Therefore, the failure to confirm the original four-factor solution in this RKI-M is not surprising.

TABLE 1 Characteristics of the study participants (*n* =143).

Variables		
Sex, *N* (%)		
Male	46	(32.2)
Female	97	(67.8)
Age (years), mean (±SD)	36.04	(6.7)
Duration working in current facility, mean in years (±SD)	11.2	(6.2)
Duration of working in psychiatric services: mean in years (±SD)	8.5	(7.5)
Ethnicity, *N* (%)		
Malay	108	(75.5)
Chinese	12	(8.4)
Indian	17	(11.9)
Others	16	(4.2)
Occupation, *N* (%)		
Psychiatrist	18	(12.6)
Psychologist	5	(3.5)
Staff nurse	40	(28.0)
Medical assistant	16	(11.2)
Psychiatry trainee	16	(11.2)
Psychiatric medical officer	41	(28.7)
Occupational therapist	7	(4.9)
Study location, *N* (%)		
Teaching hospital (Urban)	58	(40.6)
Ministry of health hospital (Urban)	65	(45.5)
Ministry of health hospital (Rural)	20	(14.0)

In our study, five out of seven items were loaded on Factor 1 (roles and responsibility) and all six items were loaded on Factor 2 (non-linearity of the recovery process), based on the original factor structure (4). These findings are consistent with several other studies that reported similar item loading on Factor 1 (21, 24, 26). Carvalho and Chima (24) found that taking a single factor structure and renaming Factor 1 as a 'recovery process' rather than 'roles and responsibility' was more inclusive of Recovery. These two studies that used the method of exploring the factors and confirming it with CFA came out with a similar construct. However, the omission of 10 questions and the existence of a potential second factor would indicate that the concept of recovery is not entirely integrated into the single factor structure (24, 25). In this aspect, the RKI-M proved to have a better outcome with a two-factor structure and the possibility of a third factor. Further research is required to elucidate hidden items to be more in keeping with local practices.

In this RKI-M study, item 1 'the concept of recovery' is equally important in all 'phases of treatment' and item 5 'not everyone is capable of actively participating in the recovery process' representing Recovery Readiness, was removed, as it had a low factor loading. Rehabilitation which is an important part of recovery and it being seen as a return to symptom-free normalcy has been challenged in the context of mental health care. People affected by mental illness have been more vocal about expressing what makes them move beyond the status of "patient" (27). This is clearly the number one point of contention between mental health professionals in providing adequate support for people with psychiatric disorders. In addition to supporting the individual and assisting them in identifying their own strengths, practitioners must be aware of the possibilities of individuals rather than concentrating solely on the problem (28). Practitioners should cease acting like experts and let people take control of their own recovery processes by letting people choose the services they

TABLE 2 Total mean score between the 3 different hospitals based on the 11-item RKI-M (*N* =143).

Study location	Teaching hospital (Urban)			Ministry of health hospital (Urban)			Ministry of health hospital (Rural)		
	Mean	*N*	SD	Mean	*N*	SD	Mean	*N*	SD
Q1	2.93	58	1.18	3.28	65	1.34	3.70	20	1.26
Q2	4.34	58	0.61	4.48	65	0.59	4.45	20	0.51
Q3	2.03	58	0.77	2.51	65	1.15	2.70	20	1.30
Q4	3.12	58	1.01	3.18	65	1.22	3.45	20	1.28
Q5	3.05	58	1.23	3.17	65	1.40	3.30	20	1.26
Q6	3.64	58	0.79	3.72	65	0.96	4.10	20	1.07
Q7	3.53	58	0.98	4.12	65	0.80	3.95	20	1.10
Q8	4.17	58	0.65	4.29	65	0.68	4.40	20	0.60
Q9	4.34	58	0.51	4.34	65	0.62	4.30	20	0.57
Q10	3.50	58	0.92	3.60	65	1.00	3.65	20	1.14
Q11	4.28	58	0.70	4.37	65	0.67	4.60	20	0.60

TABLE 3 Descriptive statistics for the 20-item RKI-M (*N* =143).

No.	Item	Theoretical domain[a]	Mean	SD	Min.	Max.
1	The concept of recovery is equally relevant to all phases of treatment	Recovery readiness	4.66	0.70	1	5
2	People receiving psychiatric/substance abuse treatment are unlikely to be able to decide their own treatment and rehabilitation goals	Self determination	3.21[b]	1.28	1	5
3	All professionals should encourage clients to take risks in the pursuit of recovery	Risk taking	3.88	0.92	2	5
4	Symptom management is the first step toward recovery from mental illness/substance abuse	Managing symptoms	4.42[b]	0.59	2	5
5	Not everyone is capable of actively participating in the recovery process	Recovery readiness	3.78[b]	0.97	2	5
6	People with mental illness/substance abuse should not be burdened with the responsibilities of everyday life	Citizenship	2.34[b]	1.06	1	5
7	Recovery in serious mental illness/substance abuse is achieved by following a prescribed set of procedures	Individual process	4.08[b]	0.84	1	5
8	The pursuit of hobbies and leisure activities is important for recovery	Involvement in meaningful activities	4.48	0.66	2	5
9	It is the responsibility of professionals to protect their clients against possible failures and disappointments	Risk taking	3.39[b]	1.08	1	5
10	Only people who are clinically stable should be involved in making decisions about their care	Self determination	3.20[b]	1.15	1	5
11	Recovery is not as relevant for those who are actively psychotic or abusing substances	Recovery readiness	3.14[b]	1.31	1	5
12	Defining who one is, apart from his/her illness/condition, is an essential component of recovery	Redefining self	4.18	0.73	2	5
13	It is often harmful to have too high of expectations for clients	Hope	3.50[b]	1.03	1	5
14	There is little that professionals can do to help a person recover if he/she is not ready to accept his/her illness/condition or need for treatment	Incorporating illness	3.74[b]	0.92	2	5
15	Recovery is characterized by a person making gradual steps forward without major steps back	Non-linear progress	3.86[b]	0.95	1	5
16	Symptom reduction is an essential component of recovery	Managing symptoms	4.30[b]	0.66	2	5
17	Expectations and hope for recovery should be adjusted according to the severity of a person's illness/condition	Hope	4.34[b]	0.57	3	5
18	The idea of recovery is most relevant for those people who have completed, or are close to completing, active treatment	Recovery readiness	3.57[b]	0.98	1	5
19	The more a person complies with treatment, the more likely he/she is to recover	Services are not enough	4.36[b]	0.68	1	5
20	Other people who have a serious mental illness or are recovering from substance abuse can be instrumental to a person's recovery as mental health professionals	Supportive others	3.92	0.94	1	5

[a] The theoretical domain is based on 20 items from the original RKI (4).
[b] Item scores were inversed before calculating the mean and standard deviation.

want (29). Recovery is just not about services, interventions, or support, but about what people with mental disorders do to treat their condition and get their lives back on track. Consequently, recovery is not the same thing that service providers may or may not do for clients, no matter how well-intentioned or remedial they are (27). There is a misconception that recovery cannot be an "add-on" to an already-existing service, support, or system in clinical practise (30). Instead, recovery should always be the main objective of all programmes and aid, with each client having a unique recovery plan that offers a more comprehensive framework for incorporating system initiatives like evidence-based practises, cultural competency, trauma, and co-occurring conditions. To aid in recovery, a few of these factors require refocusing (31). Calls for change should, at least initially, concentrate on redesigning existing policies, practises, procedures, services, and support with an emphasis on recovery and be receptive to suggestions that include collaborative practises. More than 86% of the participants in this study came from ward settings. Thus, respondents may be defensive and prefer safety to risk-taking. This is the case in the Japanese study by Chiba et al. (21) that was conducted in an Asian setting, reflecting the similar prevailing view of prolonged hospitalization for psychiatric treatment in Malaysia (32). RKI scores in community facilities were higher than those in inpatient psychiatry, according to a follow-up study by Chiba (33), despite conflicting results from earlier studies (6, 34). Additional studies show the

TABLE 4 Confirmatory factor analysis of RKI-M.

Model	Number of items	GFI	AGFI	CFI	RMSEA	Chi-squared	df	*p*-value
4-factor	20	0.82	0.77	0.79	0.082	320.488	164	<0.001
3-factor	13	0.90	0.90	0.89	0.073	109.071	62	<0.001
2-factor	11	0.92	0.87	0.91	0.074	76.678	43	<0.001

*All factors were derived and developed from the original study of Bedregal et al. (4) to fit the Malaysian context. GFI, Goodness of Fit; AGFI, Adjusted Goodness of Fit; CFI, Confirmatory Fitness Index; RMSEA, Root Mean Square Error of Approximation; df, degree of freedom.

TABLE 5 Comparison of factor structure between the original study and this study.

Factor structure	Items based on the original study (4)	Items based on this study
Factor 1: Roles and responsibility in recovery	2, 6, 7, 9, 10, 11, 18	2, 6, 10, 11, 18
Factor 2: Non-linearity of the recovery process	4, 14, 15, 16, 17, 19	4, 14, 15, 16, 17, 19
Factor 3: The roles of self-definition and peers in recovery	1, 3, 8, 12, 20	Nil
Factor 4: Expectation regarding recovery	5,13	Nil

TABLE 6 RKI-M total mean comparison based on type of occupation (*N* =143).

Occupation	*N*	Mean	SD
Psychiatrists	18	3.30	0.42
Medical officers	57	3.49	0.49
Medical assistants and staff nurses	56	3.97	0.54
Occupational therapists and psychologists	12	3.70	0.39

challenges in providing recovery-oriented care in hospitals (35, 36). As a result, the higher RKI scores found among those with community support can be explained by the fact that these individuals are typically more exposed to social resources that promote personal recovery and have access to a greater number of individuals who have successfully completed their own recovery (37). This demonstrates how crucial it is to have a knowledgeable community psychiatry team.

Historically, Malaysia has gone through several phases of development of community psychiatric services and decentralization of services outside psychiatric hospitals since the 1970s (32). The results showed questions 13 and 20 had a low factor loading ratio, which may be attributed to the low domain of recovery knowledge of the mental health practitioners in this study. Lack of local data to support this hypothesis, reflects the lack of epidemiological studies in Malaysia that looks at mental health literacy and help-seeking behavior. Understanding of mental health and seeking help may have improved in recent years as the Malaysian media openly shares and discusses mental health issues. However, a systematic epidemiological investigation is still needed to prove this situation (38). This is undoubtedly the first point of contention among mental health professionals when it comes to giving people with psychiatric disabilities adequate support. Instead of focusing on the issue, practitioners need to be aware of everyone's options (39). Additionally, they must encourage and assist people in discovering their own strengths (28). Recovery refers to what people with mental disorders do to treat their condition and restore control of their lives, not to any service, intervention, or support. Therefore, regardless of how well-intentioned or recovery-oriented service providers may be, recovery does not equal something that service providers may or may not do for clients (27). At least initially, the focus of transformation should be on modifying and realigning current policies, practises, services, and support to be focused on promoting recovery, enacting collaborative practises, and being receptive to the idea of applying the Recovery-oriented approach' tenets.

The RKI measures risk, and among the questions it poses are those that inquire about the clinician's viewpoint on whether risk-taking should be encouraged to achieve recovery or prevented (4). Even though hope has been included in the original concept of recovery, most health care workers struggle to translate it into support for our clients, as being hopeful involves empowering clients to take therapeutic risk. Hope is mainly investigated as mechanisms related to health and quality of life that create everyday possibilities (40–42). Unfortunately, many clients experience daunting and discouraging interactions with mental health professionals due to their low expectations, which destroy hope (34). Professionals need to understand and strive to promote hope because it is these interpersonal relationships that serve as a catalyst for hope, which is critical to recovery (34). Lack of organizational support, exhaustion, burnout (43), the absence of a therapeutic relationship (44) and working with service users whose needs are complex and progress is slow (45) may all contribute to practitioners' lack of optimism (46). The literature suggests several approaches to resolving this problem, including clinical supervision for all employees and encouragement of therapeutic alliances through instruction on how to practise recovery (47). These factors may be why recovery approaches in Malaysia are hampered by a lack of resources, understanding and communication between fraternities, although we have moved to community-oriented practices since the 1970s.

One of the most important concepts in the recovery approach is the individual process and shared decision-making (SDM). Previous research in Malaysia has indicated that SDM is one of the focal points in the individual process. Although this idea is present in Malaysia, it is still in its early stages (48). In this RKI-M study, the findings show that most mental health care workers had poor knowledge on the individual process. This fact was picked up by item 7 which had a low factor loading, indicating that the knowledge of this aspect was still poor and insufficient. With the recent adoption of the National Health Plan, there are opportunities to promote SDM among the Ministry of Health, public and private health service providers, researchers, academic institutions, and to involve patients in health care decision making (48).

In order to provide the highest level of care, the World Health Organization (WHO) defines collaborative practise as multiple health professionals from diverse professional backgrounds working with patients, families, carers, and communities (49). A multidisciplinary team's members working together as well as patient and healthcare professional collaboration are both examples of broad collaboration. Due to the complexity of serious mental health issues, effective care is typically team-based, with many different specialties collaborating to assist clients while keeping in mind the preferences of service users. It is considered important to develop cooperative practices in Malaysia, as qualitative studies have shown that interactions are often hierarchical rather than supportive. This scenario sometimes negatively affects patient care, for example, when the nurse does not inform the doctor in charge that the treatment plan is not working or that patient has stopped taking the drug because of side effects. For example, services are often fragmented because there is little exchange of information between psychiatric hospitals and health clinics. Even in primary care, there is a treatment gap of over 90%. Cultural factors influence how people work together, and caregiving models are typically developed in Western settings, so they may not be the best caregiving models for Asian environments, rendering poor representations (50).

This study revealed an intriguing finding: Staff nurses, medical assistants, and other members of the allied health services seemed to know more about recovery than psychiatrists and medical officers, who had a lower total mean knowledge score. Perhaps this result could be explained by the two different approaches used in the undergraduate training modules that either use the recovery model or the medical model. Randomized controlled trials have shown that mental health user-trained professionals have higher rates of positive recovery than expert-trained professionals (51). Other researchers have discovered that recovery training programmes could indeed change practitioners' attitudes, knowledge, and hopefulness (52–54). A study done among nurses in Italy, shows that gender and age to play a role in recovery knowledge and its implementation (55). It will be interesting to do this in future studies among student nurses as well as to analyze their age and gender and seeking out if indeed current syllabus and age does affect recovery knowledge.

The World Health Organization (WHO) observes the development of mental health as an important task in the coming years. WHO uses several strategies to achieve this goal and one of them is the promotion of Recovery-orientated treatment (56). Despite the limitations brought on by the illness, the emphasis is on leading a fulfilling, hopeful life and being able to contribute to society (47). There are two popular types of recovery: "Personal recovery," which is typically said to be based on the experiences of people living with mental illness; and "clinical recovery," which derives from the knowledge of mental health professionals and includes symptom relief, restoration of social functioning, and support for patients to "get back to normal" (57). Organizational commitment, individualized recovery, and positive working relationships are essential elements (58) however, medical treatment typically take center stage in acute care facilities. Psychosocial interventions may be less frequently used in these settings because of the impact this medical focus has on mental health professionals working there (59–63). Health professionals often take a symptom-focused approach to mental health care, which can undermine the development and implementation of Recovery practices (64).

The concept of 'recovery' developed in Western countries differs from that developed in Asian countries and in English-speaking countries (65) leading to only the first two factors to be being similar to Bedregal et al.'s (4) the original RKI study by Bedregal et al. (4), and the and possibility of poor recovery knowledge among the Malaysian mental health care workers. The cultural context is also important when examining mental health beliefs. Cultural differences by race have led to different definitions of mental health (66). An important part of mental health in Malaysian culture has to do with spiritual and religious factors (67). Malays associate mental illness with the term's "madness" or "gila" or "sakit jiva" (disease of the soul). Mental disorders are generally considered paranormal rather than clinically confirmed symptoms. The general perception of mental illness is typically expressed because of rejecting or ignoring traditional values, so Malaysian culture itself has a significant impact on society (68). The majority ethnic group in Malaysia, the Malays, believe that mental illness has a supernatural origin, which is a form of divine punishment, or is the result of excessive mental effort (69). Similar to Malay culture, traditional Chinese medicine, which is based on Confucianism and Taoism, has an influence on how the Chinese view mental health (70). The majority of Chinese believe that an imbalance between yin and yang can result in mental illness, and these principles are related to the idea of yin and yang as a symbol of life (70). Hinduism's view of mental health is based on the idea that the four purposes of life—Dharma, Karma, Artha, and Moksha—are reflected in a mind–body dichotomy. Hindus believe that these four components are out of balance in those who suffer from mental illness (71). Cultures and religions have a significant impact on culturally sensitive aspects of religions and belief systems. The use of traditional treatments for mental illness in society may be to blame for this predicament. Mental health professionals, who make up a sizable portion of the community, are plagued by the stigma of public political hype about mental health in their day-to-day work. Hence, future studies ought to concentrate on the cultural specificity of recovery attitudes and information.

There are very few published recovery-intervention studies using validated tools and training programmes (72). However, there are frequently discussed interdisciplinary approaches to community care that are published. For instance, Slade et al. multi-site randomized controlled trial in 2015 that investigated behaviorally focused interventions by mental health team members to enhance recovery support for people with mental illness (REFOCUS) (73). To this date, no recovery-intervention study has still not been done in Malaysia and little efforts taken to standardize quality measures of mental health care locally and around the world. In addition to enabling quality improvement at the provider, clinic, and health system levels, systematic measurement and reporting of healthcare quality also makes it possible for accountability mechanisms like financial penalties, public accountability, and compensation (74). It is challenging to evaluate the quality of mental health care globally because it varies from one nation to another and from one service provider to another (75). Hence, it is not only important to define outcome measures but to have consistent outcome measures first before being able to conduct valid and actionable studies. Existing e-health systems lack the ability to systematically collect data, which can hinder continuous improvement in patient quality (75). To ease this problem, mental health professionals recommend the systematic use of outcome measures using intervention-based therapy. The weak infrastructure within health systems here in Malaysia, make it complicated to have measured outcomes, and this is especially true given the numerous barriers to mental health, including policy and technological limitations, and limited scientific evidence on qualitative measures of mental health. There is inadequate training and support for healthcare providers and cultural barriers to integrating mental health services into the general healthcare environment. There are many gaps in the scientific basis for supporting mental health quality measures, particularly for consumers, as well as for the most meaningful outcomes for specific population groups, such as children. There is a lack of resources to detect and measure common psychiatric disorders in the population, such as anxiety disorders or even outcomes of evidence-based treatments such as psychotherapy. The evidence base for many other psychosocial interventions is still lacking, even though there is a well-established evidence base for mental health interventions like drug therapy, specialized passive psychotherapy (like cognitive behavioral therapy), and team-based interventions (like community mindfulness therapy) (76). Evidence-based psychotherapy is currently subject to quality standards that may not accurately reflect how well it is delivered.

Collaboration in client treatment has been hampered by varying definitions of recovery. Research on the recovery model has produced a complex definition over time with no apparent agreement. Battersby and Morrow (61) conducted a conceptual analysis and discovered that different disciplines, including social work, nursing, and psychology, have different definitions of recovery. However, according to literature review, quality of life, self-determination, empowerment, hope, meaningful roles, peripheral effects of serious mental illness, support system, and distinctive treatment are among the factors that define recovery (77–82). To streamline the dissemination of knowledge and research on the recovery model, researchers looked at the various definitions of recovery that are currently in use and identified recurring themes (77, 83, 84). In this study we have attempted to explore the Malaysian understandings of Recovery knowledge and to extrapolate the local influences. Nevertheless, action has been hampered by a lack of agreement on what constitutes operational and measurable recovery among healthcare professionals, the research community, and most crucially, mental health consumers (85). It's not always necessary to expect self-report scales to have high internal consistency. This is due to the fact that individuals are knowledgeable in some fields but not in others (21). Therefore, the low reliability observed in this study seems to be understandable because the RKI is a measure for assessing human knowledge. The 11 RKI-M items' validity and reliability are somewhat supported by this study, but modifications will be needed in follow-up research. Wilrycx et al. (23) reported that the organization and presentation of RKI entries is complicated and challenging to interpret. Following careful consideration of RKI-M representations and conceptual equivalence, it allows for a clearer conceptualization of "retrieval knowledge and retrieval relationships" in the context of the original RKI.

5. Limitations

There are some limitations on this study. First, test–retest reliability was not evaluated. Second, registered nurses, medical assistants, and psychiatry medical officers made up 75% of the total study population. Consequently, the generalizability of our findings might only apply to these professions. AGFI was a borderline good fit as AMOS requires a minimum sample size of 300. Third, the English language, when translated into Bahasa Malaysia, could prove to have low-level comprehension and may not be very suitable for allied health professionals, as the words used are more formal and less intricate. There is also a more specific need to understand the concept of the recovery approach before one can complete the questionnaire. Differences could have arisen because of the translation of the items from English to Bahasa Malaysia. During the translation process, issues arose, for instance, finding equivalent words in Bahasa was difficult for some items that were just extremely difficult to understand. A simpler-worded Bahasa questionnaire would be better and could be used for both professional health care workers and allied health workers. Fourth, differences may arise because of the way mental health care is organized in Malaysia. For instance, the multi-cultural society is unfamiliar with consumer-run initiatives, particular recovery tenets, managed care, or collaborating with individuals who have personally dealt with psychiatric issues.

6. Conclusion

This study investigated the factor validity and internal consistency of the Bahasa Malaysia version of the RKI among mental health professionals. The 20-item RKI-M was reliable but had poor construct validity. However, the modified 11-item-Malay version of RKI is a more reliable measure and had with a good construct validity. Malaysian cultural settings influenced the two-factor structure in the present study. Omitted items do not consistently measure the same concept in the definition of recovery. CFA found a third factor, but there were insufficient entries for this factor, resulting in a low Cronbach's alpha. This result may indicate the possibility of a hidden factor. The authors humbly recommend the use of both models in future studies. EFA should be performed to find the factors in the first sample, then CFA should be applied to the second sample. The current scale can be used for future studies in Malaysia, but future large-scale studies are needed for reliable validation.

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 Medical Research and Ethics Committee, National University of Malaysia. The patients/participants provided their written informed consent to participate in this study.

Author contributions

TM, SL, FA, and MM conceptualized this study. SL was involved in the database collection and organization of this study. KT and SL and were responsible for data analysis. SL, TM, FA, KT, and MM were responsible for interpretation of study results and involved in the writing and review of the final draft of this manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The study's authors affirm that there were no financial or commercial ties that might be viewed as having a potential conflict of interest.

Publisher's note

References

1. Anthony WA. Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabil J*. (1993) 16:11–23. doi: 10.1037/h0095655

2. Davidson L, O'Connell M, Tondora J, Styron T, Kangas K. The top ten concerns about recovery encountered in mental health system transformation. *Psychiatr Serv*. (2006) 57:640–5. doi: 10.1176/ps.2006.57.5.640

3. Leamy M, Bird V, Le Boutillier C, Williams J, Slade M. Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *Br J Psychiatry*. (2011) 199:445–52. doi: 10.1192/bjp.bp.110.083733

4. Bedregal LE, O'Connell M, Davidson L. The recovery knowledge inventory: assessment of mental health staff knowledge and attitudes about recovery. *Psychiatr Rehabil J*. (2006) 30:96–103. doi: 10.2975/30.2006.96.103

5. Evans MH. Book Review: Hannah Graham, Rehabilitation Work. Supporting Desistance and Recovery. *European J Prob*. (2017) 9:196–8. doi: 10.1177/2066220317723535

6. Cleary A, Dowling M. Knowledge and attitudes of mental health professionals in Ireland to the concept of recovery in mental health: a questionnaire survey. *J Psychiatr Ment Health Nurs*. (2009) 16:539–45. doi: 10.1111/j.1365-2850.2009.01411.x

7. Gudmundsson E. Guidelines for translating and adapting psychological instruments. *Nordic Psychology*. (2009) 61:29–45. doi: 10.1027/1901-2276.61.2.29

8. Talbert M, Brandt BA, McKown S, Gawlicki MC, Heinzman A, Polltiz A. Dual Back translation versus single Back-translation methodology when translating patient reported outcomes (PRO). *Value Health*. (2013) 16:A596. doi: 10.1016/j.jval.2013.08.1674

9. In J. Introduction of a pilot study. *Korean J Anesthesiol*. (2017) 70:601–5. doi: 10.4097/kjae.2017.70.6.601

10. Van Teijlingen E, Hundley V. The importance of pilot studies. *Nurs Stand*. (2002) 16:33–6. doi: 10.7748/ns.16.40.33.s1

11. Whitehead AL, Julious SA, Cooper CL, Campbell MJ. Estimating the sample size for a pilot randomised trial to minimise the overall trial sample size for the external pilot and main trial for a continuous outcome variable. *Stat Methods Med Res*. (2016) 25:1057–73. doi: 10.1177/0962280215588241

12. Rouquette A, Falissard B. Sample size requirements for the internal validation of psychiatric scales. *Int J Method Psychi Res*. (2011) 20:235–49. doi: 10.1002/mpr.352

13. Hair J. F. (2009). Multivariate data analysis.

14. Memon MA, Ting H, Ramayah T, Chuah F, Cheah JH. A review of the methodological misconceptions and guidelines related to the application of structural equation MODELING: a MALAYSIAN scenario. *J Appl Struct Equation Model*. (2017) 1:i–xiii. doi: 10.47263/jasem.1(1)01

15. Cerny BA, Kaiser HF. A study of a measure of sampling adequacy for factor-analytic correlation matrices. *Multivar Behav Res*. (1977) 12:43–7. doi: 10.1207/s15327906mbr1201_3

16. Bentler PM. Comparative fit indexes in structural models. *Psychol Bull*. (1990) 107:238–46. doi: 10.1037/0033-2909.107.2.238

17. Cuttance P. (1987). Issues and problems in the application of structural equation models.

18. Byrne BM. *Structural Equation Modeling With AMOS: Basic Concepts, Applications, and Programming.* Psychology Press (2001).

19. Yong AG, Pearce S. A beginner's guide to factor analysis: focusing on exploratory factor analysis. *Tutorials Quant Methods Psychol*. (2013) 9:79–94. doi: 10.20982/tqmp.09.2.p079

20. Cronbach LJ. Internal consistency of tests: analyses old and new. *Psychometrika*. (1988) 53:63–70. doi: 10.1007/BF02294194

21. Chiba R, Umeda M, Goto K, Miyamoto Y, Yamaguchi S, Kawakami N. The property of the Japanese version of the recovery knowledge inventory (RKI) among mental health service providers: a cross sectional study. *Int J Ment Heal Syst*. (2017) 11:71. doi: 10.1186/s13033-017-0178-7

22. Happell B, Byrne L, Platania-Phung C. The recovery knowledge inventory for measurement of nursing student views on recovery-oriented mental health services. *Issues Ment Health Nurs*. (2015) 36:799–808. doi: 10.3109/01612840.2015.1049310

23. Wilrycx G, Croon MA, van den Broek A, van Nieuwenhuizen C. Psychometric properties of three instruments to measure recovery. *Scand J Caring Sci*. (2012) 26:607–14. doi: 10.1111/j.1471-6712.2011.00957.x

24. Carvalho J, Chima FO. Exploratory and confirmatory factor analysis of mental health recovery knowledge inventory. *Am Int J Contemp Res*. (2019) 9:1–9. doi: 10.30845/aijcr.v9n3p1

25. Ofina MS. *Attitudes toward and knowledge of recovery-oriented care among community mental health providers: An exploratory and confirmatory factor analysis of the recovery knowledge inventory (RKI). Doctoral dissertation*. Alliant International University (2016).

26. Ofina M, Ja DY, Prentiss D, Cooper B. *Attitudes and Knowledge of Recovery-oriented Care with Community Mental Health Providers: An analysis of the Recovery Knowledge Inventory (RKI).* Washington DC: American Psychological Association (2014).

27. Slade M, Amering M, Farkas M, Hamilton B, O'Hagan M, Panther G, et al. Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems. *World Psychiatry*. (2014) 13:12–20. doi: 10.1002/wps.20084

28. Marnetoft SU, Selander J. Multidisciplinary vocational rehabilitation focusing on work training and case management for unemployed sick-listed people. *Int J Rehabil Res*. (2000) 23:271–9. doi: 10.1097/00004356-200023040-00003

29. Rapp CA, Goscha RJ, Carlson LS. Evidence-based practice implementation in Kansas. *Community Ment Health J*. (2010) 46:461–5. doi: 10.1007/s10597-010-9311-7

30. Gyamfi N, Bhullar N, Islam MS, Usher K. Knowledge and attitudes of mental health professionals and students regarding recovery: a systematic review. *Int J Ment Health Nurs*. (2020) 29:322–47. doi: 10.1111/inm.12712

31. Meehan T, Glover H. Using the recovery knowledge inventory (RKI) to assess the effectiveness of a consumer-led recovery training program for service providers. *Psychiatr Rehabil J*. (2009) 32:223–6. doi: 10.2975/32.3.2009.223.226

32. Abu Bakar AK. Community psychiatric Services in Malaysia: where do we go from here? *Malays J Psychiatry*. (2011) 20:537. doi: 10.1007/978-1-4302-3298-8_49

33. Chiba R, Umeda M, Goto K, Miyamoto Y, Yamaguchi S. Factors related to recovery knowledge and attitudes among professionals in mental health in Japan. *Japan J Nurs Sci*. (2020) 17:e12295.

34. Gaffey K, Evans DS, Walsh F. Knowledge and attitudes of Irish mental health professionals to the concept of recovery from mental illness–five years later. *J Psychiatr Ment Health Nurs*. (2016) 23:387–98. doi: 10.1111/jpm.12325

35. Chen SP, Krupa T, Lysaght R, McCay E, Piat M. The development of recovery competencies for in-patient mental health providers working with people with serious mental illness. *Admin Policy Mental Health Mental Health Serv Res*. (2013) 40:96–116.

36. Piat M, Sabetti J, Bloom D. The transformation of mental health services to a recovery-oriented system of care: Canadian decision maker perspectives. *Int J Soc Psychiatr*. (2010) 56:168–77.

37. Price-Robertson R, Obradovic A, Morgan B. Relational recovery: beyond individualism in the recovery approach. *Adv Ment Health*. (2017) 15:108–20. doi: 10.1080/18387357.2016.1243014

38. Midin M, Zainal NZ, Lee TC, Ibrahim N. Mental health services in Malaysia. *Taiwanese J Psychiatry (Taipei)*. (2018) 32:281–93.

39. Egeland KM, Benth JŠ, Heiervang KS. Recovery-oriented care: mental health workers' attitudes towards recovery from mental illness. *Scand J Caring Sci*. (2021) 35:998–1005. doi: 10.1111/scs.12958

40. Russinova Z. Providers' hope-inspiring competence as a factor optimizing psychiatric rehabilitation. *J Rehabil*. (1999) 65:50–7.

41. Sachse D. Hope: more than a refuge in a storm. a concept analysis using the Wilson method and the Norris method. *Int J Psychiatr Nurs Res*. (2007) 13:1546–53.

42. Cutcliffe JR, Barker P. Considering the care of the suicidal client and the case for 'engagement and inspiring hope'or 'observations'. *J Psychiatr Mental Health Nurs*. (2002) 9:611–21.

43. Morse G, Salyers MP, Rollins AL, Monroe-DeVita M, Pfahler C. Burnout in mental health services: a review of the problem and its remediation. *Adm Policy Ment Health Ment Health Serv Res*. (2012) 39:341–52. doi: 10.1007/s10488-011-0352-1

44. Browne G, Cashin A, Graham I. The therapeutic relationship and mental health nursing: it is time to articulate what we do! *J Psychiatr Ment Health Nurs*. (2012) 19:839–43. doi: 10.1111/j.1365-2850.2012.01944.x

45. Hovey T, Cheswick C. Copying letters to service users with learning disabilities: opinions of service users, carers and professionals working within learning disability services. *Br J Learn Disabil*. (2009) 37:50–5. doi: 10.1111/j.1468-3156.2008.00506.x

46. Zeyada M. Organizational culture and its impact on organizational citizenship behavior. *Int J Acad Res Bus Social Sci*. (2018) 8:418–29. doi: 10.6007/IJARBSS/v8-i3/3939

47. Slade M. The contribution of mental health services to recovery. *J Ment Health*. (2009) 18:367–71. doi: 10.3109/09638230903191256

48. Lee YK, Ng CJ. The state of shared decision making in Malaysia. *Z Evid Fortbild Qual Gesundhwes*. (2017) 123:66–8. doi: 10.1016/j.zefq.2017.05.019

49. Funk M, Organization WH, Minoletti A. *Mental Health Policy, Plans and Programmes.* World Health Organization (2005).

50. Shoesmith W, Chua SH, Giridharan B, Forman D, Fyfe S. Creation of consensus recommendations for collaborative practice in the Malaysian psychiatric system: a modified Delphi study. *Int J Ment Heal Syst*. (2020) 14:1–14. doi: 10.1186/s13033-020-00374-7

51. Cook JA, Jonikas JA, Razzano L. A randomized evaluation of consumer versus nonconsumer training of state mental health service providers. *Community Ment Health J*. (1995) 31:229–38. doi: 10.1007/BF02188749

52. Salkeld R, Wagstaff C, Tew J. Toward a new way of relating: an evaluation of recovery training delivered jointly to service users and staff. *J Ment Health*. (2013) 22:165–73. doi: 10.3109/09638237.2012.694506

53. Crowe TP, Deane FP, Oades LG, Caputi P, Morland KG. Effectiveness of a collaborative recovery training program in Australia in promoting positive views about recovery. *Psychiatr Serv*. (2006) 57:1497–500. doi: 10.1176/ps.2006.57.10.1497

54. Higgins A, Callaghan P, DeVries J, Keogh B, Morrissey J, Nash M, et al. Evaluation of mental health recovery and Wellness Recovery Action Planning education in Ireland: a mixed methods pre–postevaluation. *J Adv Nurs*. (2012) 68:2418–28.

55. Zuaboni G, Hahn S, Wolfensberger P, Schwarze T, Richter D. Impact of a mental health nursing training-programme on the perceived recovery-orientation of patients and nurses on acute psychiatric wards: results of a pilot study. *Issues Ment Health Nurs*. (2017) 38:907–14. doi: 10.1080/01612840.2017.1359350

56. Jenkins R, Minoletti A. Promoting mental health: a crucial component of all public policy. *Health Policies*. (2013):163.

57. Shepherd G, Boardman J, Slade M. *Making Recovery a Reality*. London: Sainsbury Centre for Mental Health. (2008). p. 1–3.

58. Le Boutillier C, Slade M, Lawrence V, Bird VJ, Chandler R, Farkas M, et al. Competing priorities: staff perspectives on supporting recovery. *Admin Policy Mental Health Mental Health Serv Res*. (2015) 42:429–38.

59. Barker P, Buchanan-Barker P. Myth of mental health nursing and the challenge of recovery. *Int J Ment Health Nurs*. (2011) 20:337–44. doi: 10.1111/j.1447-0349.2010.00734.x

60. Carlyle D, Crowe M, Deering D. Models of care delivery in mental health nursing practice: a mixed method study. *J Psychiatr Mental Health Nurs*. (2012) 19:221–30.

61. Battersby L, Morrow M. Challenges in implementing recovery-based mental health care practices in psychiatric tertiary care. *Canad J Commun Mental Health*. (2012) 31:103–11.

62. Mullen A. Mental health nurses establishing psychosocial interventions within acute inpatient settings. *International Journal of Mental Health Nursing*. (2009) 18:83–90. doi: 10.1111/j.1447-0349.2008.00578.x

63. Cleary M, Horsfall J, Hunt GE, Escott P, Happell B. Continuing challenges for the mental health consumer workforce: A role for mental health nurses?. *Int. J Mental Health Nur*. (2011) 20:438–44.

64. Cusack E, Killoury F, Nugent LE. The professional psychiatric/mental health nurse: skills, competencies and supports required to adopt recovery-orientated policy in practice. *J Psychiatr Ment Health Nurs*. (2017) 24:93–104. doi: 10.1111/jpm.12347

65. Tse S, Davidson L, Chung KF, Ng KL, Yu CH. Differences and similarities between functional and personal recovery in an Asian population: a cluster analytic approach. *Psychiatry*. (2014) 77:41–56. doi: 10.1521/psyc.2014.77.1.41

66. Hungerford C, Dowling M, Doyle K. Recovery outcome measures: is there a place for culture, attitudes, and faith? *Perspect Psychiatr Care*. (2015) 51:171–9. doi: 10.1111/ppc.12078

67. Hassan MF, Hassan NM, Kassim ES, Hamzah MI. Issues and challenges of mental health in Malaysia. *Int J Acad Res Bus Social Sci*. (2018) 8:1685–96. doi: 10.6007/IJARBSS/v8-i12/5288

68. Haque A. Culture-bound syndromes and healing practices in Malaysia. *Ment Health Relig Cult*. (2008) 11:685–96. doi: 10.1080/13674670801958867

69. Swami V, Loo PW, Furnham A. Public knowledge and beliefs about depression among urban and rural Malays in Malaysia. *Int J Soc Psychiatry*. (2010) 56:480–96. doi: 10.1177/0020764008101639

70. Yip KS. Family intervention and services for persons with mental illness in the People's Republic of China. *J Fam Soc Work*. (2005) 9:65–82. doi: 10.1300/J039v09n01_04

71. Wig NN. Mental health and spiritual values. A view from the east. *Int Rev Psychiatry*. (1999) 11:92–6. doi: 10.1080/09540269974230

72. Waldemar AK, Arnfred SM, Petersen L, Korsbek L. Recovery-oriented practice in mental health inpatient settings: a literature review. *Psychiatr Serv*. (2016) 67:596–602. doi: 10.1176/appi.ps.201400469

73. Slade M, Bird V, Clarke E, Le Boutillier C, McCrone P, Macpherson R, et al. Supporting recovery in patients with psychosis through care by community-based adult mental health teams (REFOCUS): a multisite, cluster, randomised, controlled trial. *Lancet Psychiatry*. (2015) 2:503–14. doi: 10.1016/S2215-0366(15)00086-3

74. Institute of Medicine (IOM). Roundtable on Evidence-Based Medicine. *The Learning Healthcare System: Workshop Summary*. In: Olsen L, Aisner D, McGinnis JM, editors. Washington, DC: The National Academies Press (2007).

75. Kilbourne AM, Beck K, Spaeth-Rublee B, Ramanuj P, O'Brien RW, Tomoyasu N, et al. Measuring and improving the quality of mental health care: a global perspective. *World Psychiatry*. (2018) 17:30–8. doi: 10.1002/wps.20482

76. Committee on Developing Evidence-Based Standards for Psychosocial Interventions for Mental Disorders: Board on Health Sciences Policy: Institute of Medicine. In: England MJ, Butler AS, Gonzalez ML, editors. *Psychosocial Interventions for Mental and Substance Use Disorders: A Framework for Establishing Evidence-Based Standards*. Washington (DC): National Academies Press (US). (2015). Available at: https://www.ncbi.nlm.nih.gov/books/NBK305126/ doi: 10.17226/19013

77. Davidson L, Tondora J, O'Connell MJ, Kirk TJ, Rockholz P, Evans AC. Creating a recovery-oriented system of behavioral health care: moving from concept to reality. *Psychiatr Rehabilit J*. (2007) 31:23–31. doi: 10.2975/31.1.2007.23.31

78. Farkas M, Gagne C, Anthony W, Chamberlin J. Implementing recovery oriented evidence based programs: identifying the critical dimensions. *Commun Mental Health J*. (2005) 41:141–58.

79. O'Connell M, Tondora J, Croog G, Evans A, Davidson L. From rhetoric to routine: assessing perceptions of recovery-oriented practices in a state mental health and addiction system. *Psychiatr Rehabilit J*. (2005) 28:378–86.

80. Kalk K. (2015). *Advancing Recovery C Ollaborative A Breakthrough Series*, California Institute for Behavioral Health Solutions. United States of America. Retrieved from https://policycommons.net/artifacts/1643264/a-dvancing-r-ecovery-c-ollaborative-a-breakthrough-series/2337302/ on 26 Apr 2023. CID: 20.500.12592/0gv99b.

81. Onken SJ, Craig CM, Ridgway P, Ralph RO, Cook J. An analysis of the definitions and elements of recovery: A review of the literature. *Psychiatr Rehabilit J*. (2007) 31:9–22.

82. Davidson L, O'Connell MJ, Tondora J, Lawless M, Evans AC. Recovery in Serious Mental Illness: A New Wine or Just a New Bottle? *Professional Psychology: Research and Practice*. (2005) 36:480–7. doi: 10.1037/0735-7028.36.5.480

83. Armstrong NP, Steffen JJ. The recovery promotion fidelity scale: assessing the organizational promotion of recovery. *Commun Mental Health J*. (2009) 45:163–70.

84. Moran GS, Zisman-Ilani Y, Garber-Epstein P, Roe D. Adaptation and psychometric assessment of the Hebrew version of the Recovery Promoting Relationships Scale (RPRS). *Psychiatric Rehabilitation Journal*. (2014) 37:31–6. http://doi.org/10.1037/prj0000043

85. McCance-Katz EF. The substance abuse and mental health services administration (SAMHSA): new directions. *Psychiatr Serv*. (2018) 69:1046–8. doi: 10.1176/appi.ps.201800281

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Parental stress in families of children with special educational needs: a systematic review

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Background: This systematic review aimed to identify the risk factors and protective factors for parental stress in families with children with special educational needs. Studies have indicated that the wellbeing of families is related to the physical, psychological, and social conditions of the children, as well as the family functioning, stress coping strategies, and social and professional support of their parents. The parents of children with special educational needs experience high levels of parental stress. Identifying the associated risk factors and protective factors may shed light on the provision of interventions to promote the mental wellbeing of these parents.

Methods: Boolean operators were used to search multiple online databases, and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines were applied in this systematic review. Data were extracted into categories of population, age, region, the child's diagnosis, the stress-measuring instrument, and the risk factors and protective factors.

Results: Twenty-six studies, including 5,169 parents and 3,726 children, were reviewed. The following four major risk factors and protective factors were found to be associated with parental stress: the sex of the parents, diagnosis-related coping issues, socioeconomic characteristics, and social isolation of the parents.

Conclusions: This systematic review identified four significant risk factors and protective factors related to social support from couples, family members, and social circles. Various agencies may provide financial and manpower assistance and professional support and services to improve the parents' knowledge and coping skills, as well as affectional support, early screening, and continuous assessment of the parents' progress. Social policies and interventions offering continuous and diagnosis-related support to the parents of children with special educational needs are highly recommended.

KEYWORDS

parental stress, special educational needs, parental stress assessment tool, systematic review, coping

Introduction

Over 291 million children and adolescents younger than 20 years globally were estimated to have developmental disabilities and special educational needs (1). These children may have disabilities, such as intellectual disability, epilepsy, hearing or vision loss, autism spectrum disorder (ASD), or attention deficit hyperactivity disorder (2). Parenting a child with SEN may be a wonderful journey with a sense of accomplishment and excitement, but it may also be challenging or even impose a caregiving burden (3).

Parents of children with SEN may be prone to psychological distress, such as anxiety, sleep disturbances, and frustration, when facing the behavioral problems of their children (4, 5). For example, a study by Caley (6) found that the mother, as the primary caretaker of SEN experienced higher stress levels. Stress may come from managing the challenging behavior and special needs of children. Aif et al. (7) concluded that parents bringing up children with SEN face overall family life changes, and burdens affect many aspects of life. Prolonged stress from handling children's daily-life problems and diverse and challenging needs may affect family functioning and wellbeing (8, 9). Parents may also feel stress and experience additional financial strain when taking care of their children who have SEN in combination with fluctuating health conditions or the requirement for repeated hospitalization (10–12).

The impact of taking care of children with SEN is multifaceted. It is not uncommon for such parents to have marital problems, physical and psychological distress, or mental health issues (13–15). Studies have provided some hints of the possible factors contributing to the mental wellbeing of the parents of children with SEN. For example, families who receive services designed based on person-centered and family-centered approaches have been found to experience less marital stress. These families may develop more appropriate or adaptive techniques to take care of their children and may feel more supported by healthcare service providers (3). Psychoeducation programs designed to address the challenging behavior and health conditions of children with SEN (e.g., ASD) have been shown to effectively reduce the maternal burden (16).

To improve the wellbeing of the parents or informal caregivers of children with SEN, it is essential to identify the risk factors and protective factors for stress in this population. The aim of this study was to identify the risk factors and protective factors affecting the stress level of the parents of children with SEN. A better understanding of these factors may help to provide guidelines for service providers to design effective interventions (17–19).

Methods

Operation definition

This is a systematic review of studies on stress experienced by the parents of children (aged 3–17) with SEN. In this paper, SEN include specific learning difficulties, intellectual disability, ASD, attention deficit hyperactivity disorder, physical disability, visual impairment, hearing impairment, and speech and language impairments (20). Parent-related stress represents the level of dysfunction in the parent–child system related to the parent's functioning (15).

Article selection

The initial search was first applied to the Cochrane Database of Systematic Reviews to determine if any previous reviews covered our topic. After confirming that there was no equivalent review, an extended search was conducted.

This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses protocols (21). Boolean searches were used to interrogate PubMed, Embase, Cochrane Library, PsycINFO (via ProQuest), and Web of Science databases. Studies published from 1960 to 2021 were searched. The following search terms were entered into the databases: "parental stress," "special educational needs," "risk factor," and "stress level measurement." The detailed search terms included "parental stress AND special educational needs," "parental stress AND special educational needs and/or disabilities," "parental stress AND special educational needs AND measuring risk level," "parental stress AND special educational needs AND level of risk," "parental stress AND special educational needs AND risk factor," "parental stress AND special educational needs AND stress level measurement," "parental stress level measurement AND special educational needs," "parenting stress level measurement AND special educational needs," and "parent stress level AND special educational needs."

Articles were included in the analysis if:

- they reported primary research investigating stress experienced by the mother, father, or both parents of children with SEN, with at least one quantitative measurement or in a qualitative format;
- they were published in a peer-reviewed journal; and
- the full-text publication was available in English.

Articles were excluded if:

- they reported a study unrelated to parental stress or
- they reported secondary research or were a conference presentation or unpublished thesis.

The primary database search identified 3,092 records. Information was imported to EndNote 20 (Clarivate, London, UK) for the deduplication process to eliminate redundant data. After completing this process, 2,524 articles were excluded. In addition, 169 articles were excluded as they were not relevant. Another 169 articles were excluded as they did not evaluate both parental stress and SEN. Another 204 articles were excluded because they reported secondary research, consisted of a manuscript or conference material with an abstract only, or did not report parental stress. No further eligible studies were identified during the manual screening process. Finally, 26 articles were included in this systematic review. The details of the screening process, which followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (22), are described in Figure 1.

Results

Description of the articles reviewed

After screening the articles, relevant data were extracted and summarized in tabular format. The characteristics of the included studies are summarized in Table 1.

This review covered 26 studies, which included seven studies from the USA; five from Europe; and 14 from Asia, including five from China and Hong Kong. Of these 26 studies, 11 involved ASD, six involved ADHD, and 11 involved intellectual disability. For the articles involving intellectual disability, different terms, such as cognitive delay

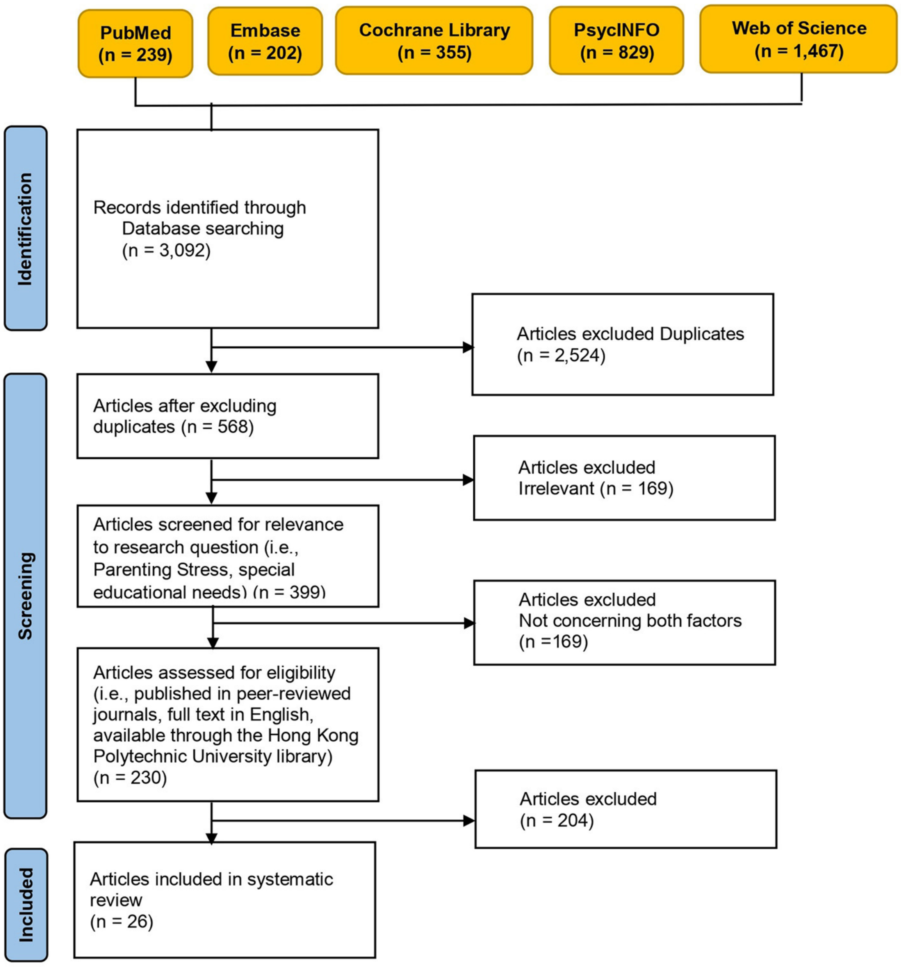

FIGURE 1
Preferred reporting items for systematic reviews and meta-analyses flow chart of the screening process.

(34), intellectual disability (30, 31), and mental disability (42), were applied.

Risk factors and protective factors

The following four major categories of risk factors and protective factors were identified: the sex of the parents, diagnosis-related coping issues, socioeconomic characteristics, and social isolation of the parents.

Sex of the parents

Mothers were reported to perceive more parental stress than fathers in four studies, mainly due to their labor workload and their need to handle unpredictable situations (28–30, 36). Only one study reported the same stress level between mothers and fathers in 15 families (39). Parental stress was found to increase with the increasing age of the parents (29).

Diagnosis-related coping issues

Twelve studies reported that the major risk factors were the challenging behavior or maladaptive behavior of children with SEN. Behavioral problems related to ASD or ADHD or the emotional problems of children with SEN were related to higher levels of parental stress (23–25, 27, 28, 31, 33, 35, 39, 47). Higher levels of emotional problems of SEN children, higher parental stress were recorded. Parents who do not have adequate professional or social support may develop poor parenting practices. Negative coping habits or handling methods may result from the lack of appropriate knowledge and competence to handle stressful situations (24, 31, 32, 43).

Protective factors, such as professional support (23, 25, 27–32, 34, 35, 41, 44), and positive coping skills and techniques, such as stress management strategies, were related to lower levels of parental stress (31, 42, 45, 47). That is, a better understanding of the child's progress and gaining knowledge and skills to manage the behaviors of children with SEN were also protective factors.

Furthermore, a study of parents reported that those who knew the diagnosis of their child since birth were able to adjust their expectations (23). For example, the parents were able to cope better if the cognitive deficits of their children were identified at birth, rather than acquired later.

Socioeconomic characteristics

Having financial problems (31, 34, 45) and a family's lower socioeconomic level (44, 46) were related to higher levels of parental stress in parents of children with SEN compared with parents of typically developing children.

Five studies (31, 34, 44–46) from countries including Israel, Vietnam, Malawi of Africa, and China reported that financial issues were a risk factor, but parents demonstrated hesitation and resistance to seek financial assistance due to social pressure and associated feelings of shame about disclosing the family's situation. Another two studies found that the self-disclosure of the family's information and needs when approaching government services was a source of shame and conflict with other family members.

Social isolation of parents

Five studies reported that social isolation and a poor social life were sources of parenting burdens and increased the stress level of parents (24, 31–33, 43). This occurred because the lack time for oneself and insufficient social support may increase perceived levels of stress. Another three studies reported that poor family support induced extra stress during the caregiving journey (37, 38, 43). Four studies indicated that stigma and judgment from others induced stress in the parents of children with SEN (25, 31, 40, 47).

However, it was found that supportive family and marital relationships and sufficient labor help were protective factors. Support from professionals (25, 27–29, 31, 32, 37, 41, 42, 45, 47) and family members (7, 26, 27, 29, 44) were factors contributing to a reduction in the levels of parental stress. Regarding family support, four studies showed that positive marital relationships and support from spouses were essential protective factors (35, 38, 39, 44). Three studies conducted in the Asian region: Jordan, Malaysia, and Israel (30, 37, 40) indicated that strong family support promoted a positive perception of the parental task as a challenge rather than a burden. Sufficient professional services were found to be useful for improving the mindfulness and attitudes of the parents (25) and their knowledge of disease and behavioral management (29, 32, 45, 47). Ongoing assessments of the parenting situation (41) and stress management techniques (30, 42, 47) may also reduce parental stress. Thirteen studies applied the Parenting Stress Index–Short Form to evaluate parental stress.

Discussion

Sex of the parents

The results indicated that there were differences in parental stress levels between fathers and mothers, with mothers perceiving higher stress levels than fathers. A higher stress level may be induced by closer interactions with children to handle behavior related to their diagnosis. Role identification within the family may be one of the underlying reasons for this finding; that is, the father may focus on breadwinning rather than caring or daily house activities. A heavy workload for the daily care of children and more frequent interactions with problematic behavior were some of the sources of parental stress. The major caring role was shouldered by the mother, leading to higher stress levels for mothers. Studies (48, 49) have shown that parental stress is induced by heavy physical and psychological burdens related to daily caring and continuous worrying about the child's future. This may have negative effects on the entire family system and directly impact the quality of life of the whole family (50–52). In China, mothers generally take greater responsibility for childcare than fathers (45). Mothers face unique challenges in handling SEN children's emotional and behavioral symptoms. The mothers may perceive being left alone in the caring duties as they play a significant role in raising SEN children. When adequate external support is available, the mothers may gain confidence to adopt a more positive living style. Professional support may include caring techniques, knowledge of SEN, and information on available services. Direct intervention from different professions may reduce parental stress more effectively.

The father was identified as an immeasurable source of support (39), Further studies on how the family role and the father–child relationship affect parental stress are recommended. In the meanwhile, service providers may consider to actively involve father into training as a partner, to fully utilize their strengths to support their spouses. Adequate support to fathers and recognitions afterwards are therefore foundations to development of fathers.

Diagnosis-related coping issues

For diagnosis-related issues, one of the identified risk factors was handling the challenging behavior of the children. The underlying deficits leading to the challenging behavior of children with SEN are varied. The lack of knowledge and skills in behavioral management of children with SEN may induce negative coping behaviors (e.g., reacting with anger), which cause further anxiety and stress to the parents (6, 53). Therefore, diagnosis-specific psychoeducation programs (e.g., knowledge of the specific conditions of children with SEN and parenting, behavioral management, problem-solving, and stress management skills) would be helpful to reduce the stress levels of the parents (5, 10, 54).

Formal support from professionals and government policy may provide structured and sustainable assistance to parents to improve their knowledge and skills to handle problems or crisis in daily care. The informal support system, on the other hand, including

TABLE 1 Characteristics of the reviewed articles.

References	Population and age	Region	Diagnosis	Stress measurement tools	Risk factors/protective factors
Spratt et al. (23)	- Mother and father total 181 - Children population not mentioned - 4–12 yrs old	USA	- Combined developmental, behavioral, neurological, and emotional problems (DBC) - Intraventricular hemorrhage documented at birth (IVH) - Learning and/or attention problems (LD/ADHD) - Neural tube defects (NTD)	Parenting stress index Short Form (PSI/SF)	Risk factors: - Behavioral problems of child Protective factors: - Parents such as those with IVH and NTD know from birth that their children might have cognitive difficulties and are able to adapt their expectations and/or coping accordingly
Muñoz-Silva et al. (24)	- Mother 126 - Boy 90, girl 36 - 6–17 yrs old	Spain	ADHD	- Parenting stress index Short Form (PSI/SF) - Stress index for parents of adolescents (SIPA)	Risk factors: - Negative impact on social life - Conduct problems Protective factors: - Not mentioned
Shaffer et al. (25)	- Mother 11 - Children 15 - Age not mentioned	USA	ADHD/ADD, autism, anxiety, dyspraxia or dysgraphia, dyslexia, speech related disorder, fragile-X syndrome	- Depression Anxiety and Stress Scales (DASS-SS) - The Perceived Stress Scale (PSS) - Structured, open-ended questions to collect qualitative results	Risk factors: - Contrasting perspectives regarding child’s needs and proposed solutions (perceive more therapy or medication) - Parents’ thoughts and emotions associated with worries about current and future situations - Child’s behaviors and special needs - Perceived judgment from others - Educational barriers (limitation for school or educators) - Parent is not engaging in self-care or restorative activities Protective factors: - Sense of community/Feeling a sense of belonging - Awareness of the need for self-care - Mindfulness-based practices and attitudes (become more aware of your own actions)
Zeng et al. (26)	- Parent 226 - Child 216 - Age not mentioned	China	ASD	Parenting stress index Short Form (PSI/SF)	Risk factors: - Insufficient respite care service - Lack of services to provide emotional health Protective factors: - Family support on parental stress - Support group for parents to learn from each other
Sarimski et al. (27)	- Mother 115, father 10 - Children population not mentioned - Age not mentioned	Germany	Intellectual disabilities, hearing impairment or visual impairment	Parenting stress index Short Form (PSI/SF)	Risk factors: - Child behavioral problems - Category of disability: more stress in intellectual disability, than visual impairment, than deaf. Determined by a heterogeneous group of variables including child disability itself Protective factors: - Actively participate in therapeutic activities - Sufficient professional support - Family support
Roccella et al. (28)	- Parent 330 - Boy 173, girl 157 - 5.8–11.6 yrs old	Italy	Primary monosymptomatic nocturnal enuresis (PMNE)	Parenting stress index Short Form (PSI/SF)	Risk factors: - Characteristic of diagnosis: uncontrollable and unpredictable situation - Mother reported more stress than father Protective factors: - Psychological support on emotional dimensions from professional.

(Continued)

TABLE 1 (Continued)

References	Population and age	Region	Diagnosis	Stress measurement tools	Risk factors/protective factors
Feizi et al. (29)	- Mother 285 - Children population not mentioned - 6–12 yrs old	Iran	Chronic physical diseases (diabetes, epilepsy, renal problems, and leukemia), difficult sensory-motor and intellectual problems (blindness, deafness, intellectual disability, cerebral palsy), psychological disorder (scolionophobia, autism, ADHD, conduct disorder, oppositional defiant disorder, and learning disability)	- Parenting stress index Short Form (PSI/SF) - Mean Mother = 116, father = 106	Risk factors: - More stress on mother of children with sensory-motor mental and chronic physical problems, than psychological disorders Protective factors: - Professional support on diagnostic knowledge and professional consultation on stress management
Obeidat (30)	- Mother 53, father 45 - Children population not mentioned - 4–11 yrs old	Jordan	Type 1 diabetes mellitus	Parenting stress index Short Form (PSI/SF)	Risk factors: - Mother reported more stress than fathers - Increasing age of parents - Challenges of caring for lifelong illness Protective factors: - Professional support through educational program in terms of disease management - Psychological support from nurse
Leyser and Dekel (31)	Family 82, mother 77, father 26	Israel	Learning disabled, intellectual disability, organic disability (impairments to central nervous system), autistic, developmentally delayed, physically impaired	Structured interview	Risk factors: - Financial problems - Support from community - Feelings of stigma - Time available for special child and siblings - Unacceptable behaviors of disabled, need for continued care, lack of time for themselves Protective factors: - Support from health care professionals (counseling, training on knowledge, practical skills, in-depth family therapy) - Maintain close contacts with extended family members (e.g., own parents)
Park and Yoon (32)	- Mother 5 - Children population not mentioned - Age not mentioned	Korean	Deaf	Qualitative research, one-to-one, in-depth, semi structured interviews with participants in their native Korean language	Risk factors: - Frustration with parenting their child - Struggling between mainstream education and special education - Continuing to be alienated from mainstream education settings - Feeling left out and hurt in family relationships - Making a sacrifice for the child - Change in values of life - Importance of services meeting parents' needs Protective factors: - Physician had provided support in regard to the psychological and emotional aspects, and detailed information on approaches to handling deafness
Chan et al. (33)	- Mother 560, father 150 - Boy 615, girl 95 - School age	HK	Polymorbidity: language disabilities, ASD, ADHD, specific learning disability, intellectual disability	Parenting stress index Short Form (PSI/SF) Chinese version	Risk factors: - Developmental polymorbidity condition brings higher level of parenting stress, physical and emotional strain, child problem behaviors and emotional symptoms give up valued activities Protective factors: - Not mentioned

(Continued)

TABLE 1 (Continued)

References	Population and age	Region	Diagnosis	Stress measurement tools	Risk factors/protective factors
Shin and Nhan (34)	- Mother 225 - Boy 135, girl 65	Vietnam	Cognitive delay	Parenting stress index Short Form (PSI/SF) Likert response categories simplified to 1–3	Risk factors: - Having a child of cognitive delay, mother's education—fewer coping strategies, father's health condition—financial burden, economic status—lack of resources Protective factors: - Social support
Weitlauf et al. (35)	- Mother 70 - Children population not mentioned - Age not mentioned	USA	ASD	Parenting stress index Short Form (PSI/SF)	Risk factors: - Child challenging behavior - Autism symptoms or cognitive abilities - Less positive marital relationship exacerbate the impact of parenting stress Protective factors: - Positive martial relationship buffer the impacts of parenting stress
Gerstein et al. (36)	- Family 115 - 3–5 yrs old	USA	Intellectual disabilities (ID)	Parenting daily hassles (PDH)—to measure daily parenting stress	Risk factors: - Mothers experienced higher stress than fathers Protective factors: - Not mentioned
Chu et al. (37)	- Parent 110 mother 80, father 30 - Children population not mentioned - Age not mentioned	Malaysian	ASD	- Affiliate Stigma Scale - Caregiver Burden Inventory	Risk factors: - Without assistance in caring of child - Time-demanding tasks - Relational problems with the child Protective factors: - Do not possess negative views about themselves - Malays are found to be the most supportive and less rejecting of individuals with mental disorders - Formal professional support such as therapy, or informal support - Parents adopt positive meanings to their experience in order to repossess a sense of control over their lives as a means to buffer their stress
Chan and Mo (38)	- Mother 18, father 2 - Children 20 - 7–12 yrs old	China	Dyslexia alone, or with ADHD	In-depth interview	Risk factors: - Conditions come with diagnosis, daily responsibilities and maternal role inequalities, social comparisons and promoting a parent-blaming culture, competitive school culture with high expectations on academic result and heavy homework load Protective factors: - Placing more value on children's "other strength", cultural and religious beliefs to reframe current situation, active communication with teachers, enhance support from spouses
Arif et al. (7)	- Mother 415, father 32, - School age 150	Pakistan	Mild, moderate, and severe disability from three special schools	Coping Strategies Inventory (CSI)	Risk factors: - Parents who perceive the child's disability as a burden or some sort of tension face a high level of stress and they mostly blame themselves for the child's disability Protective factors: - Parents who perceive the presence of disability in their family as a challenge experience lower level of stress
Hadadian (39)	- Family 15 - Boy 8, girl 7 - 20–48 months old	USA	Developmental delay, physically or sensory impaired (from early childhood special education programs)	- Parent Stress Index-—101 items - Parental questionnaire	Risk factors: - Children's behavior and temperament - Stress level of mother = father Protective factors: - Mothers who receive support from their spouses (fathers as a source of support) - Parents' strength and needs were recognized and supported by professional communities

(Continued)

TABLE 1 (Continued)

References	Population and age	Region	Diagnosis	Stress measurement tools	Risk factors/protective factors
Duvdevany and Abboud (40)	- Mother 100 - Boy 54, girl 45 - Age 4–12 years old	Israel	Intellectual disability (ID)	- Emotional Stress Perception Scale - Arabic version	Risk factors: - Self-disclosure of family information and needs when approaching government service, as a source of shame and conflict with family Protective factors: - Strong family support by relatives as in traditional Israeli Arab society
Macias et al. (41)	- Boy 99, girl 71 - Age 4–12 years old	USA	Children with Special Health Care Needs (CCSHCN): Neural tube defects (NTD), Developmental-behavioral disabilities (DBD), or history of Perinatal intraventricular hemorrhage (IVH)	- Parenting stress index Short Form (PSI/SF)	Risk factors: - Children have toileting problem Protective factors: - Clinicians in primary care settings provide assessment and referral - Professional support like counseling or other psychological services - Clinicians provide ongoing stress appraisals to monitor progress
Jones (42)	Parent 13	UK	Recognized physical or intellectual disability	Questionnaire for feedback, non-standardized tool	Risk factors: - Not mentioned Protective factors: - Adopt stress management skills from profession, in group format in terms of counseling, Rational Emotive Therapy, hypnosis and time management
De Clercq et al. (43)	- Mother 415, father 32 - Children 447 - School age 6–17	Belgium	Autism spectrum disorder, cerebral palsy, Down syndrome	- Parenting Stress Index (PSI 40 items) - Dutch version	Risk factors: - Role restriction, marital stress, attachment stress, competence stress, feelings of social isolation Protective factors: - Not mentioned
Ren et al. (44)	- Mother 1,049, father 402 - Children 1,451 - Preschool 97 - School age 1,354	China	Autism, intellectual disability, hearing impairment, visual impairment	- State Anxiety Inventory (S-AI) - Parenting Stress Index—Short Form-15 (PSI-SF-15) - NEO Five-Factor Inventory (NEO-FFI) - Multidimensional Scale of Perceived Social Support (MSPSS)	Risk factors: - Family's socioeconomic level declines, not able to go to school normally during epidemic, lack of professional support Protective factors: - College education or above, monthly family income above 15,000 CNY, higher material wellbeing, job satisfaction, and family satisfaction
Huang et al. (45)	- Mother 80 - Children 80 - Pre-school 65, School-age 15	China	Autism spectrum disorder (ASD), including low and high functioning ASD	Parenting stress index Short Form (PSI/SF)	Risk factors: - Financial issue, such as cost of interventions and treatment for children with ASD is often not covered by insurance Protective factors: - Social supports: better knowledge of behavior management through both education and receipts of ASD services, multidisciplinary parent education program designed for caregivers
Masulani-Mwale et al. (46)	Parents 170	Malawi, Africa	Intellectual disabilities	Self-Reporting Questionnaire (SRQ)	Risk factors: - Lower socioeconomic status, single motherhood, perceived burden of care, low confidence in managing the disabled child, lack of psychosocial support, knowledge of child's disability and having more than one child with a disability in the family Protective factors: - Not mentioned
Li et al. (47)	- Mother 20, father 2 - Children 25	USA	Autism spectrum disorder (ASD)	Parenting stress index Short Form (PSI/SF)	Risk factors: - Autism diagnosis, challenging child behaviors, stigma and marginalization, and financial burden Protective factors: - Behavioral interventions for stress management with particular focus on their parenting role

support from family members, relatives and friends, and even neighborhoods, can act as a moderating factor to reduce parental stress and improve the wellbeing of mothers (40). Multiple studies indicated social support is an essential protective factor to reduce perceived parental stress (39, 44, 47). Some parents may consider their social life is being sacrificed. Muñoz-Silva et al. (24) found that the strongest predictor of mothers' stress is the negative impact on their social life, but not the children's emotional problems nor the mothers' perceived social support. Therefore, the parent's social life should be considered when designing an improvement plan for the family.

Because of negative coping habits or handling methods, parents have a feeling of shame when children exhibit uncontrollable challenging behavior in a social environment (40) and they blame themselves (7, 38) or have low confidence in managing their children with SEN (46). Long-term follow-up by a professional is recommended. For example, professionals may provide ongoing monitoring of the parents' stress levels and refer them to suitable professional services as required.

Socioeconomic characteristics

Financial and human resource constraints may be some of the major risk factors for parental stress, as parents from lower socioeconomic levels need extra support for expenses and manpower to care for their children with SEN (55). For example, the parents of children with SEN may perceive extra physical, time, and financial concerns when bringing their children to receive treatment. To minimize the traveling costs, telehealth or tele-rehabilitation may be alternative options to support the parents. However, further enhancement of telehealth or tele-rehabilitation systems is needed. Government policies on financial support for the parents of children with SEN are also recommended.

Social isolation of parents

Emotional support was one of the main protective factors identified. Professional staff may provide opportunities for parents to express their concerns, unmet needs, and worries. Social groups were able to provide opportunities for parents to share their unique stories with others with similar experiences. Studies have also suggested the importance of social relationships in reducing parental stress (3, 6).

Chu et al. (37) conducted a study which recruited 110 parents of children with ASD, with 80 mothers and 30 fathers, with ages mainly around 21–50, from an online support group. It was found that although stressful situations and parenting difficulties occurred due to time-demanding tasks required by the children, parents expressed that affiliate stigma does not affect their stress levels and even quality of life. It is worth to note that the participants were active support group members who shared knowledge and offered social support in caring for ASD children. The members of this support group were also exposed to massive amounts of information and experience sharing and also receiving therapy from different professionals. Sharing positive coping strategies can tackle stress associated with feelings of helplessness and isolation (56). This indicates some essential features of peer support group that may help reducing parental stress. Cultural factors should be considered as 93.6% of the participants in that study are Malay. Malay perceives the child as a form of test from God, and parents will be judged in the afterlife (57). This may have an impact on the view of caring duties of caring for their children with SEN.

Limitations

This systematic review has several limitations. First, most of the research participants were mothers (3,585 mothers and 699 fathers). The participants joined the studies voluntarily, but actively participating attendants may have a more positive attitude, which may have biased the results. Second, not all studies included a control group or applied a randomized control trial in the research design. Third, the screening, selection, and data extraction processes were performed by a single researcher. Therefore, further studies on parental stress experienced by fathers, performed with the involvement of a second researcher are recommended.

Conclusions

This systematic review synthesized recent findings on the risk factors and protective factors for parental stress in the families of children with SEN. Regarding risk factors, handling the challenging behavior of children is the major component of diagnosis-related coping issues. Financial problems and lower socioeconomic levels restricted the time and resources to care for SEN children. Social isolation of parents is considered as a risk factor caused by poor social life, insufficient family support, and even stigma and judgment from others. On the other hand, protective factors such as professional support can improve positive coping skills and gain a better understanding of a child's progress. Supporting family systems and positive marital relationships can lead to better resilience and coping techniques for parents, leading to better wellbeing.

Healthcare professionals have a unique role in remediating parents' burdens. Parents expected a gracious explanation or time from professionals. Parents treasured being taken by the professionals seriously. Considering the parental stress induced by taking caring of SEN children, healthcare professionals can act as a source of information and direct support as well as assisting parents in developing positive coping techniques. A valid parental stress assessment is essential. It is noticed that the most commonly applied parental measurement tool by healthcare professionals was the Parenting Stress Index-Short Form. Moreover, measurement tool identifying the risk factor and protector factor would be needed to promote the resilience of the parents.

Parenting a child with SEN may be a complicated and demanding task, which may lead to additional financial, physical, psychological, and social burdens. This review identified the possible risk factors and protective factors for parental stress, with the aim of identifying ways to relieve this stress.

The findings from the reviews suggest when identified parents of SEN with high stress, service provider should provide choices of stress-relieving programs, direct assistance in manpower or financial issue, and also provide professional opinion to develop positive handling technique. When existing services cannot fulfill particular needs, referral to health care professionals should be considered, in order to design custom made program. It may guide the practice of service providers. The development of diagnosis-specific parental support programs and future studies on their impact on parents with different family roles are recommended.

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

AC and CL designed the review. AC conducted the systematic review and prepared the tables and figures. CL edited the review. All authors contributed to the article and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

1. Olusanya BO, Boo NY, Nair MKC, Samms-Vaughan ME, Hadders-Algra M, Wright SM, et al. Accelerating progress on early childhood development for children under 5 years with disabilities by 2030. *Lancet Glob Health.* (2022) 10:e438–44. doi: 10.1016/S2214-109X(21)00488-5

2. Olusanya BO, Boo NY, de Camargo OK, Hadders-Algra M, Wertlieb D, Davis AC. Child health, inclusive education and development. *Bull World Health Organ.* (2022) 100:459–61. doi: 10.2471/BLT.22.288103

3. Bruce E, Lilja C, Sundin K. Mothers' lived experiences of support when living with young children with congenital heart defects. *J Special Pediatr Nurs.* (2014) 19:54–67. doi: 10.1111/jspn.12049

4. Beckers LW, Smeets RJ, van Der Burg JJ. Therapy-related stress in parents of children with a physical disability: a specific concept within the construct of parental stress. *Disabil Rehabil.* (2021) 43:1185–92. doi: 10.1080/09638288.2019.1646815

5. Duncan LG, Coatsworth JD, Greenberg MT. A model of mindful parenting: implications for parent–child relationships and prevention research. *Clin Child Fam Psychol Rev.* (2009) 12:255–70. doi: 10.1007/s10567-009-0046-3

6. Caley LM. Risk and protective factors associated with stress in mothers whose children are enrolled in early intervention services. *J Pediatr Health Care.* (2012) 26:346–55. doi: 10.1016/j.pedhc.2011.01.001

7. Arif A, Ashraf F, Nusrat A. Stress and coping strategies in parents of children with special needs. *J Pak Med Assoc.* (2021) 71:1369–72. doi: 10.47391/JPMA.1069

8. Valicenti-McDermott M, Lawson K, Hottinger K, Seijo R, Schechtman M, Shulman L, et al. Parental stress in families of children with autism and other developmental disabilities. *J Child Neurol.* (2015) 30:1728–35. doi: 10.1177/0883073815579705

9. Mak WW, Cheung RY. Affiliate stigma among caregivers of people with intellectual disability or mental illness. *J Appl Res Intellect Disabil.* (2008) 21:532–45. doi: 10.1111/j.1468-3148.2008.00426.x

10. Jackson AC, Frydenberg E, Liang RPT, Higgins RO, Murphy BM. Familial impact and coping with child heart disease: a systematic review. *Pediatr Cardiol.* (2015) 36:695–712. doi: 10.1007/s00246-015-1121-9

11. Machalicek W, Lang R, Raulston TJ. Training parents of children with intellectual disabilities: trends, issues, and future directions. *Curr Dev Disord Rep.* (2015) 2:110–8. doi: 10.1007/s40474-015-0048-4

12. Kring SR, Greenberg JS, Seltzer MM. The impact of health problems on behavior problems in adolescents and adults with autism spectrum disorders: Implications for maternal burden. *Soc Work Ment Health.* (2010) 8:54–71. doi: 10.1080/15332980902932441

13. Aunos M, Feldman M, Goupil G. Mothering with intellectual disabilities: relationship between social support, health and well-being, parenting and child behaviour outcomes. *J Appl Res Intellect Disabil.* (2008) 21:320–30. doi: 10.1111/j.1468-3148.2008.00447.x

14. Chan W, Cao Y, Lu EY, Cheung WM, Tsang HW. Types of community support services and self-efficacy for continuous community living among individuals with disabilities and caregivers. *Int J Environ Res Public Health.* 19:12976. doi: 10.3390/ijerph191912976

15. Crnic KA, Gaze C, Hoffman C. Cumulative parenting stress across the preschool period: relations to maternal parenting and child behaviour at age 5. *Infant Child Dev.* (2005) 14:117–32. doi: 10.1002/icd.384

16. Kring SR, Greenberg JS, Seltzer MM. Adolescents and adults with autism with and without co-morbid psychiatric disorders: Differences in maternal well-being. *J Ment Health Res Intellect Disabil.* (2008) 1:53–74. doi: 10.1080/19315860801988228

17. De Gaetano K, Saviola D, Brunetti D, De Tanti A. The importance of assessing parent stress in families with children with severe neuromotor and intellectual disability - a pilot study. *Appl Neuropsychol Child.* (2022) 11:804–10. doi: 10.1080/21622965.2021.1971525

18. Keller D, Honig AS. Maternal and paternal stress in families with school-aged children with disabilities. *Am J Orthopsychiatry.* (2004) 74:337–48. doi: 10.1037/0002-9432.74.3.337

19. Miodrag N, Hodapp RM. Chronic stress and health among parents of children with intellectual and developmental disabilities. *Curr Opin Psychiatry.* (2010) 23:407–11. doi: 10.1097/YCO.0b013e32833a8796

20. Educational Bureau. *Operation Guide on the Whole School Approach to Integrated Education*. The Government of the Hong Kong Special Administrative Region (2014). Available online at: https://sense.edb.gov.hk/uploads/page/integrated-education/download-area-and-related-links/ie_guide_en.pdf (accessed July 29, 2023).

21. Moher D, Liberati A, Tetzlaff J, Altman DG. Reprint—preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Phys Ther.* (2009) 89:873–80. doi: 10.1093/ptj/89.9.873

22. Shamseer L, Moher D, Clarke M, Ghersi D, Liberati A, Petticrew M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. *BMJ.* (2015) 349:g7647. doi: 10.1136/bmj.g7647

23. Spratt EG, Saylor CF, Macias MM. Assessing parenting stress in multiple samples of children with special needs (CSN). *Fam Syst Health.* (2007) 25:435–49. doi: 10.1037/1091-7527.25.4.435

24. Muñoz-Silva A, Lago-Urbano R, Sanchez-Garcia M, Carmona-Márquez J. Child/adolescent's ADHD and parenting stress: the mediating role of family impact and conduct problems. *Front Psychol.* (2017) 8:2252. doi: 10.3389/fpsyg.2017.02252

25. Shaffer EJ, Lape JE, Salls J. Decreasing stress for parents of special needs children through a web-based mindfulness program: a pilot study. *Int J Allied Health Sci Pract.* (2020) 18. doi: 10.46743/1540-580X/2020.1887

26. Zeng S, Hu X, Zhao H, Stone-MacDonald AK. Examining the relationships of parental stress, family support and family quality of life: a structural equation modeling approach. *Res Dev Disabil.* (2020) 96:103523. doi: 10.1016/j.ridd.2019.103523

27. Sarimski K, Hintermair M, Lang M. Parent stress and satisfaction with early intervention services for children with disabilities - a longitudinal study from Germany. *Eur J Spec Needs Educ.* (2013) 28:362–73. doi: 10.1080/08856257.2013.797706

28. Roccella M, Smirni D, Smirni P, Precenzano F, Operto FF, Lanzara V, et al. Parental stress and parental ratings of behavioral problems of enuretic children. *Front Neurol.* (2019) 10:1054–1054. doi: 10.3389/fneur.2019.01054

29. Feizi A, Najmi B, Salesi A, Chorami M, Hoveidafar R. Parenting stress among mothers of children with different physical, mental, and psychological problems. *J Res Med Sci.* (2014) 19:145–52.

30. Obeidat HM. Parenting stress among parents of children with type 1 diabetes mellitus. *Curr Pediatr Res.* (2020) 24:226–32.

31. Leyser Y, Dekel G. Perceived stress and adjustment in religious jewish families with a child who is disabled. *J Psychol.* (1991) 125:427–38. doi: 10.1080/00223980.1991.10543305

32. Park J, Yoon J. A phenomenological study of parenting stress among Korean mothers of deaf children. *Am Ann Deaf.* 163:440–62. doi: 10.1353/aad.2018.0028

33. Chan RC, Yi H, Siu QK. Polymorbidity of developmental disabilities: additive effects on child psychosocial functioning and parental distress. *Res Dev Disabil.* (2020) 99:103579–103579. doi: 10.1016/j.ridd.2020.103579

34. Shin JY, Nhan NV. Predictors of parenting stress among vietnamese mothers of young children with and without cognitive delay. *J Intellect Dev Disabil.* (2009) 34:17–26. doi: 10.1080/13668250802690914

35. Weitlauf AS, Vehorn AC, Taylor JL, Warren ZE. Relationship satisfaction, parenting stress, and depression in mothers of children with autism. *Autism.* (2014) 18:194–8. doi: 10.1177/1362361312458039

36. Gerstein ED, Crnic KA, Blacher J, Baker B. Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *J Intellect Disabil Res.* (2009) 53:981–97. doi: 10.1111/j.1365-2788.2009.01220.x

37. Chu SY, Park H, Lee J, Shaharuddin KKB, Gan CH. Self-stigma and its associations with stress and quality of life among Malaysian parents of children with autism. *Child Care Health Develop*. (2020) 46:485–94. doi: 10.1111/cch.12771

38. Chan TS, Mo YK. The socio-cultural interpretation of parental stress of chinese parents of children with dyslexia: implications for social work practice. *Child Adolesc Soc Work J.* (2023) 40:131–41. doi: 10.1007/s10560-021-00753-0

39. Hadadian A. Stress and social support in fathers and mothers of young children with and without disabilities. *Early Educ Dev.* (1994) 5:226–35. doi: 10.1207/s15566935eed0503_4

40. Duvdevany I, Abboud S. Stress, social support and well-being of arab mothers of children with intellectual disability who are served by welfare services in Northern Israel. *J intellect Disabil Res.* (2003) 47:264–72. doi: 10.1046/j.1365-2788.2003.00488.x

41. Macias MM, Roberts KM, Saylor CF, Fussell JJ. Toileting concerns, parenting stress, and behavior problems in children with special health care needs. *Clin Pediatr.* (2006) 45:415–22. doi: 10.1177/0009922806289616

42. Jones PR. Stress management for parents of children with special educational needs. *Educ Psychol Pract.* (1991) 6:194–8. doi: 10.1080/0266736910060404

43. De Clercq LE, Prinzie P, Warreyn P, Soenens B, Dieleman LM, De Pauw SS. Expressed emotion in families of children with and without autism spectrum disorder, cerebral palsy and down syndrome: relations with parenting stress and parenting behaviors. *J Autism Dev Disord.* (2022) 52:1789–806. doi: 10.1007/s10803-021-05075-9

44. Ren J, Li X, Chen S, Chen S, Nie Y. The influence of factors such as parenting stress and social support on the state anxiety in parents of special needs children during the COVID-19 epidemic. *Front Psychol.* (2020) 11:565393. doi: 10.3389/fpsyg.2020.565393

45. Huang XQ, Zhang H, Chen S. Neuropsychiatric symptoms, parenting stress and social support in Chinese mothers of children with autism spectrum disorder. *Curr Med Sci.* (2019) 39:291–7. doi: 10.1007/s11596-019-2033-3

46. Masulani-Mwale C, Kauye F, Gladstone M, Mathanga D. Prevalence of psychological distress among parents of children with intellectual disabilities in Malawi. *BMC Psychiatry.* (2018) 18:146–146. doi: 10.1186/s12888-018-1731-x

47. Li XS, Pinto-Martin JA, Thompson A, Chittams J, Kral TV. Weight status, diet quality, perceived stress, and functional health of caregivers of children with autism spectrum disorder. *J Special Pediatr Nurs.* (2018) 23:e12205. doi: 10.1111/jspn.12205

48. Davis NO, Carter AS. Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: associations with child characteristics. *J Autism Dev Disord.* (2008) 38:1278–91. doi: 10.1007/s10803-007-0512-z

49. Falk NH, Norris K, Quinn MG. The factors predicting stress, anxiety and depression in the parents of children with autism. *J Autism Dev Disord.* (2014) 44:3185–203. doi: 10.1007/s10803-014-2189-4

50. Davis K, Gavidia-Payne S. The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *J Intellect Dev Disabil.* (2009) 34:153–62. doi: 10.1080/13668250902874608

51. Hsiao YJ, Higgins K, Pierce T, Whitby PJS, Tandy RD. Parental stress, family quality of life, and family-teacher partnerships: families of children with autism spectrum disorder. *Res Dev Disabil.* (2017) 70:152–62. doi: 10.1016/j.ridd.2017.08.013

52. McCabe H. The importance of parent-to-parent support among families of children with autism in the People's Republic of China. *Int J Disabil Dev Educ.* (2008) 55:303–14. doi: 10.1080/10349120802489471

53. Burgdorf V, Szabó M, Abbott MJ. The effect of mindfulness interventions for parents on parenting stress and youth psychological outcomes: a systematic review and meta-analysis. *Front Psychol.* (2019) 10:1336. doi: 10.3389/fpsyg.2019.01336

54. Lee SH, Ahn SC, Lee YJ, Choi TK, Yook KH, Suh SY. Effectiveness of a meditation-based stress management program as an adjunct to pharmacotherapy in patients with anxiety disorder. *J Psychosom Res.* (2007) 62:189–95. doi: 10.1016/j.jpsychores.2006.09.009

55. Whiteside-Mansell L, Ayoub C, McKelvey L, Faldowski RA, Hart A, Shears J. Parenting stress of low-income parents of toddlers and preschoolers: psychometric properties of a short form of the parenting stress index. *Parent Sci Pract.* (2007) 7:26–56. doi: 10.1080/15295190709336775

56. Reinke JS, Solheim CA. Online social support experiences of mothers of children with autism spectrum disorder. *J Child Fam Stud.* (2015) 24:2364–73. doi: 10.1007/s10826-014-0039-9

57. Isa SNI, Aziz AA, Ab Rahman A, Ibrahim MI, Ibrahim WPW, Mohamad N, et al. The impact of children with disabilities on parent health-related quality of life and family functioning in Kelantan and its associated factors. *J Dev Behav Pediatr.* (2013) 34:262–8. doi: 10.1097/DBP.0b013e318287cdfe

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Work-related participation impairments and support needs of patients in a Swiss psychiatric university hospital

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Objective: To assess work-related participation impairments and support needs of adult patients in inpatient and day-care treatment at a Swiss psychiatric university hospital.

Methodology: Cross-sectional survey on a department-dependent cut-off date in May and June 2022 using a standardized structured interview.

Results: Data were available for 93 patients (response rate 59%), of which 51% (*n* = 47) stated that they had a job or training place. Patients in first hospitalization and with a job or training place were approached significantly more often. Regardless of age and first hospitalization, 76% of the patients expressed a need for support, of which 92% expressed interest in job coaching. A total of 54% of the patients stated that they had received support from the treatment team.

Conclusion: From the patients' point of view, work and education were not addressed by the treatment team across the board and independently of patient characteristics. The need for support was insufficiently met. There is a considerable interest for support programs through job coaching, and this offers opportunities to promote the inclusion of patients in the regular labor market.

KEYWORDS

work-related participation, return to work, inpatient psychiatric treatment, psychiatric disorder, job coaching

Introduction

The importance of work goes beyond mere subsistence and remuneration. Work can create identity, help people find meaning and value, enable self-efficacy and ultimately define social status (1, 2). Work and mental health are closely linked (3). Work serves as an important resource for maintenance and recovery of mental health (2). Conversely, unemployment has been shown to lead to clustered health care use due to increased psychological distress and physical discomfort, and is ultimately associated with higher mortality rates (4–6). Being out of work can have far-reaching consequences on activities and participation for those affected (7). For example, lower life satisfaction, stigmatization, loss of self-esteem and social contacts. People without work are 1.7 to 3.5 times more likely to suffer from mental health problems (3). Furthermore, unemployment can also have indirect effects on those affected, for example through a lower income or the associated loss of opportunities for participation and fixed daily and time structures (8, 9).

Education is considered an important protective factor against unemployment and for maintaining mental and physical health. The level of education affects the occupational status and thus also influences the working conditions and income, the individual health attitude and the health behavior of a person (3). Education enables a more competent handling of the structures of the health system and health-related information (10). It has been shown that people who have no education beyond compulsory education are more frequently affected by mental health problems (3). In addition, migration has been shown to be a possible cause of increased psychosocial stress due to lower socioeconomic status and poorer living and working conditions (11). Of the first-generation migrant population in Switzerland (around 30%), 20–29% report psychological complaints, depending on the age group (3).

International figures on employment rates for people with severe mental illness vary widely by country and region and may also be influenced by factors such as societal attitudes, policies and support systems in place. For schizophrenia in Europe, it is assumed that only 10–20% have a job (12). In the United States in particular, the figures are unclear. Studies in Germany showed that “effective interventions to promote work-related participation” are not used enough in inpatient psychiatric treatment (13). This is despite the fact that people with mental illness have an interest in working in the primary labor market (13, 14). Accordingly, only two thirds of people succeed in re-entering the workplace after leaving hospital without help (15). In this context, it is necessary to optimize the interface between the social insurance system and health care by specifically promoting reintegration (7, 16), as is also addressed in the report “The Future of Psychiatry in Switzerland” (17).

Current figures from the Swiss Disability Insurance (IV) indicate a trend reversal in the total number of insured persons. After the total number of all IV pensioners in Switzerland declined from 2005 to 2019, a steady increase has been recorded in the last 3 years. This is in particular caused by new pensions due to mental illnesses. Almost every second new pension is now granted due to a mental illness. In 2021, around 50% of the causes of disability for a pension were due to mental illnesses. This makes it the most frequent cause, ahead of other illnesses (31%), birth defects (13%) and accidents (6%) (18). This shows that current measures to improve the participation situation of people with mental illnesses are currently not effective enough or are taken too late. Early support on the topic of work is central to preventing long-term exclusion from the labor market (19, 20).

In a survey of 176 patients in inpatient treatment at a Berlin clinic, Jäckel et al. (13) showed that 63% of the patients surveyed had a need for support. The interest in participating in job coaching was also correspondingly high. Furthermore, the results of the survey show that 49% of the patients had been approached about the topic of work. Overall, however, only 20% received concrete offers of help. According to the results, people who were ill for the first time and young adults in particular indicated a strong need for support (13). On admission to hospital, 34% (13) of psychiatric hospitalized persons had a job or training place. In view of the importance of the topic, especially in the context of mental illness, the authors point to an urgent need for action.

Work is an important issue in the treatment of people with mental illness (1, 21, 22). It should be considered and dealt with at an early stage in the context of psychiatric treatment in order to be able to agree on and initiate measures to support work and professional employment if necessary (21). It seems to be important to identify the needs of the patients. Studies on work-related participation impairments and a work-related need for support in day-care and inpatient psychiatric treatment do not yet exist for Switzerland.

The aim of the present study was to assess work-related impairments in participation and the need for support among adult patients in day-care and inpatient treatment at a Swiss psychiatric university hospital. In addition, it was to be determined whether there are group differences within the sample with regard to the expressed need for support and the support received in terms of socio-demographic characteristics (age, educational level, migration background), diagnosis, first-time hospitalized patients and patients with or without a job/training place.

Materials and methods

The UPK Basel has a mandate to provide care for the canton of Basel-Stadt with a catchment area of about 195,000 inhabitants. They provide treatment services for adult (UPKE) and child and adolescent psychiatry (UPKKJ), and have a forensic clinic and a private clinic. This ensures treatment for the entire spectrum of psychiatric illnesses. For the inpatient care of patients, around 300 inpatient treatment places are available at the UPK Basel in the four specialized clinics.

The anonymous patient survey was classified by the Ethics Committee Northwestern and Central Switzerland (EKNZ) as quality assurance not subject to approval. All patients aged 18–65 years who had been in inpatient treatment for at least 5 days in the survey period May/June 2022 and who agreed to participate in the study were taken into account. During the survey period, a cut-off date was formulated for each department, on which the survey was conducted in each case. A total of 15 departments of the UPKE and the private clinic were included.

The only exclusion criterion was florid psychotic symptoms. The fulfillment of the inclusion and exclusion criteria was assessed in each case by a responsible specialist of the corresponding department (as a rule, the respective head of the nursing department). The computer-assisted key date survey was carried out by various specialists from nursing and social services. In order to ensure a standardized implementation of the survey, the interviewers were instructed in a session and an online tutorial with an exemplary survey was made available.

The survey was conducted as an interview using a version of the standardized survey instrument by Jäckel et al. (13) adapted for Switzerland. The adapted survey instrument can be found in Supplementary Appendix 1. The central questions from it are listed below.

- “Are you currently in regular employment or training?”
  - if “no”: Is employment/training an issue for you in principle?

- "Do you need help with re-entering employment (work/training)/finding a suitable job/training place, or with vocational (re)orientation?"
- "Do you have any concerns about taking up (re-entering) employment/training?"
- "Which areas do you worry about taking up (re-entering) work/training?"
- "Have you been approached or encouraged to approach the topic of work/training here in the clinic (UPK)?"
- "Have you already received concrete support in the clinic (UPK) on the subject of work/training?"
- "Which path (direct entry into the 1st labor market with support or gradual entry in a protected environment for the time being) or do you prefer for (re-)entry?"
- "Would you be interested in taking part in a job coaching/support programme?" [note: individualized job coaching according to supported employment and its fidelity scale (23)]

It was possible to interrupt or discontinue the survey at any time. In addition, the highest level of education, migration background and psychiatric utilization (first inpatient treatment) were collected. The information on psychiatric main and secondary diagnoses, age and gender was taken from the hospital information system.

The analysis plan was based on the comparative study from Germany (13) and was designed as follows: The central questions on the "work-related participation situation," the "need for support," "having been approached about the topic during the stay," "having received concrete help during the stay" and the question on "concerns about resuming work" were coded into "presence" and "absence." Subsequently, it was analyzed for each characteristic whether the distribution of answers differed between the different groups. The groups studied were (1) patients with work and patients without work, (2) patients up to 35 years of age and patients over 35 years of age, (3) first hospitalized and re-hospitalized and (4) F-main diagnostic groups, (5) educational attainment and (6) migration background. The two age groups were defined on the basis of the average age of the sample ($M = 36.0$) and correspond to those in the analyses of the comparative study (13).

Within the framework of descriptive statistics, absolute (n) and percentage figures (%), the arithmetic mean (M) and standard deviation (SD) were calculated. To calculate the group comparisons for categorical variables, χ^2-tests were applied. For continuous variables, t-tests and Pearson correlation were applied. All statistical analyses were performed using SPSS Statistics version 27. The significance level was set at $p < 0.05$. In view of the limited number of cases and the pilot study character, a correction for multiple testing was waived.

Results

A total of 158 out of 192 patients met the inclusion criteria, of which 58.9% ($n = 93$) agreed to participate in the survey and could be interviewed. The description of the sample with socio-demographic and work-related characteristics is shown in Table 1. The characteristics of the sample were matched with the population of partial and full inpatients in the UPK. The average age (M) was significantly lower in the sample ($M = 36.0$; $M = 40.8$), and patients with an F6 (sample: 26%; population: 8%) or an F3 diagnosis (sample: 40%; population: 27%) were overrepresented in percentage terms, while F1s were underrepresented (sample: 16%; population: 39%).

Work-related participation situation

At the time of the key date survey, 49.5% ($n = 46$) were without work or without regular training or studies (hereafter: work). This status was significantly related to the highest level of education (compulsory school/secondary level II/tertiary level) (χ^2 [2.91] = 14.1; $p < 0.01$). Among the patients with compulsory school as their highest qualification, 83% ($n = 19$) were without a job. In Switzerland, compulsory school lasts 11 years and consists primary school (incl. kindergarten) and secondary school level I.

Of those without work, 80% ($n = 36$) stated that work was a relevant issue for them. Regarding age, for 8% ($n = 2$) of those under 36, work was basically not an issue; for those over 35, it was not an issue for 35% ($n = 7$) (χ^2 [1.45] = 5.06; $p < 0.05$).

At the time of the survey, 10% ($n = 9$) of the patients were not in work and at the same time stated that work was basically not an issue for them. The reasons given for this were, on the one hand, an already existing financial security, the feeling of not being able to or having no chances on the labor market, or working in a sheltered workshop without interest in a job in the primary labor market. In the following evaluations of the need for support, patients without work and without interest in work were not taken into account to ensure comparability with the study by Jäckel et al. (13).

Whether the patients were approached about the topic of work correlated significantly with the length of stay in number of days ($r = 0.26$, $p = 0.14$, $n = 93$). According to Cohen (24), this is a weak to medium effect.

Need for support with work-related participation and assistance from the treatment team

A total of 76% ($n = 63$) of patients expressed a need for support to (re)start work. Patients who were not currently in work indicated significantly more need for support (89%; $n = 32$; χ^2 [1.83] = 5.86; $p < 0.05$) than those with work (66%; $n = 31$). There were no significant differences with regard to age or whether patients were hospitalized the first time or not.

A share of 31% ($n = 29$) of the respondents preferred a direct entry into the first labor market (first place) to a gradual (re-) entry with training and preparation (40%; $n = 37$). 29% ($n = 27$) did not choose either option. Further, 79% ($n = 73$) of the interviewed patients were interested in a specific support program ("job coaching").

The interest in job coaching did not depend significantly on age or whether the patients were in work.

Overall, 77% ($n = 72$) were approached by a professional from the treatment team about the topic of work. Patients who were

TABLE 1 Sample description.

Sample description (n = 93)		Population description (Patients in the UPK may/june 2022)	
Age (M ± SD)	36.0 ± 12.7	40.8 ± 12.5	
Gender: male	51 (55%)	54%	
In work/training/study ≥15 h/week	47 (51%)	(data not available)	
Diagnose:			
F1.X	15 (16%)	F1.X	39%
F2.X	10 (11%)	F2.X	13%
F3.X	37 (40%)	F3.X	27%
F4.X	4 (4%)	F4.X	8%
F5.X	2 (2%)	F5.X	1%
F6.X	24 (26%)	F6.X	8%
F8.X	1 (1%)	F8.X	0%
		Others	4%
Comorbidity	62 (67%)	(data not available)	
In inpatient treatment for the first time	54 (58%)	(data not available)	
Not in work/training/study and without interest in (re-)starting work/training/study	9 (10%)	(data not available)	
Educational attainment:			
Compulsory school	23 (25%)	Compulsory school	28%
Secondary level II	38 (42%)	Secondary level II	42%
Tertiary level	30 (33%)	Tertiary level	21%
		No completed school education	9%
Migration:		(data not available)	
No migration background	54 (58%)		
Migration background 1st generation	18 (19%)		
Migration background 2nd generation	21 (23%)		

working (57%; n = 41) were approached significantly more often (χ^2 [1.93] = 5.24; $p < 0.05$) than patients without work/training. Also, those who were hospitalized for the first time were approached significantly more often (64%; $n = 46$; χ^2 [1.93] = 4.44; $p < 0.05$) than patients who were hospitalized more than once. In total, 71% were addressed by a social worker. A thematisation by other professional groups varied strongly, depending on the department (0–100%).

54% ($n = 39$) stated that they had received concrete help in (re-)starting work. Those over 35 years of age were significantly more likely to report having received help (71%; $n = 20$) than those under 36 years of age (43%; $n = 19$; χ^2 [1.72] = 5.50; $p < 0.05$). 90% of patients reported that they had received help from a social worker. Nursing staff (28%), psychologists (23%) and doctors (28%) were also mentioned. The help included, in particular, advice on direct (49%) or gradual/delayed (50%) (re-)entry into a job on the primary labor market as well as contacting/conversing with employers (31%).

In total, 78% ($n = 36$) of the patients with work stated that they had moderate to strong concerns about returning to work. For those without work (unemployed or retired), this was 64% ($n = 21$). Regarding the number of worries, patients of age over 35 years reported significantly more worries ($M = 2.79$; SD = 1.31; $n = 28$) compared to those of age under 36 years ($M = 2.02$; SD = 1.09; $n = 47$).

Diagnosis-related thematisation of work-related participation, support needs and assistance by the treatment team

With regard to the main diagnostic groups, differences were found with regard to work-related characteristics (Figure 1). Patients with an F6 diagnosis stated significantly more often that they had been approached about the topic of work (92%; $n = 22$) than patients with diagnostic groups F1, F2, F3, and other psychiatric disorders (72.5; $n = 50$; χ^2 [1.93] = 3.76; $p < 0.05$). At the same time, significantly less need for support was reported by the group with an F6 diagnosis (61%; $n = 14$) compared to the other diagnostic groups (82% $n = 49$; χ^2 [1.83] = 3.9; $p < 0.05$), as was help received by the group with an F6 diagnosis (32%, $n = 7$) vs. the other diagnostic groups (64%; $n = 32$; χ^2 [1.72] = 6.36; $p < 0.05$). Interest in participating in job coaching was also significantly lower among those with an F-6 diagnosis (63%; $n = 15$) vs. the other diagnostic groups (84%; $n = 58$; χ^2 [1.93] = 4.9; $p < 0.05$).

For the diagnosis-related results, a high number of comorbidities should be mentioned here. 67% ($n = 62$) of the patients had a psychiatric comorbidity due to at least two diagnoses from different F-main diagnostic groups. Patients with a diagnosis from section F6 (92%) and section F2 (70%) showed the highest comorbidity rates.

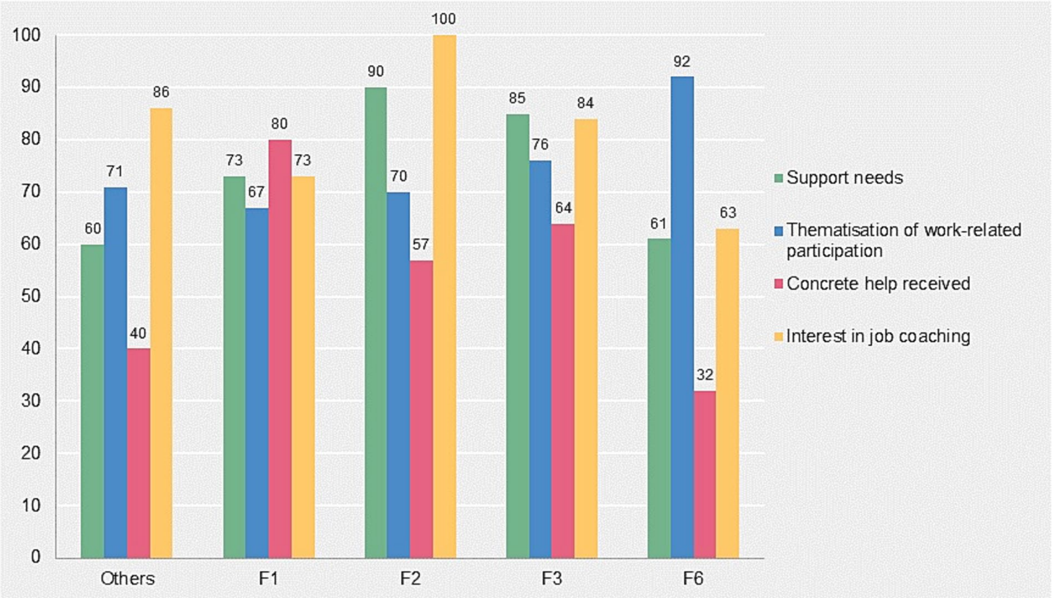

FIGURE 1
Support needs, thematisation of work-related participation, coverage of concrete help and interest in job coaching grouped by ICD-10 diagnoses (in%).

TABLE 2 Group comparison for patients with support needs and patients without support needs.

Group comparison between patients with support needs and patients without support needs (only patients with work or assessment of work as relevant *n* = 83)			
	Patients with support needs	Patients without support needs	Significance
Work addressed	49 (78%)	19 (95%)	0.08
Moderate to very strong concerns about (re-)starting work	44 (72%)	13 (65%)	0.54
Number of concerns about (re-)starting work	$M = 2.34$; $SD = 1.20$	$M = 2.19$; $SD = 1.38$	0.67
Concrete help received	31 (63%)	6 (32%)	0.02
Interest in job coaching	58 (92%)	11 (55%)	0.01

Thematisation of work-related participation, support needs and assistance by the treatment team in the different diagnostic groups

The group comparison of patients with support needs versus without support needs (Table 2) showed that the concrete help received and the interest in job coaching were significantly higher among patients with support needs. Patients without support needs, however, stated more frequently that they had been approached about the topic of work. The presence of at least moderate concerns and the number of concerns and worries, on the other hand, were not significantly higher among those who expressed a need for support.

There were no significant differences between the group of patients with a migration background and those without a migration background for any of the work- and support-related variables.

Discussion

With regard to a slight bias in the selection of the sample in terms of age and diagnoses, the present data were able to provide an insight into the patient perspective on the assessment of work-related participation limitations and the associated support needs in a Swiss psychiatric university hospital.

In comparison with the survey by Jäckel et al. (13), the present results of the key date survey also showed a very high level of interest in the topic of work on the part of the patients surveyed, while at the same time there was an unmet need for support. This is despite the fact that the topic of work was addressed more frequently in the treatment of patients at the UPK (77%) and with 42% twice as many participants stated that they had received work-related assistance compared to the survey in the psychiatric hospital in Germany. The socio-demographic data on age and gender were comparable at the two sites. The proportion of patients with jobs was also significantly higher at 51% compared to Jäckel's (13) proportion of 34%. This discrepancy could indicate differences in the Swiss and German care systems, as in the latter psychiatry and psychosomatics are organized in different care systems. Overall, a key difference between the two care systems is that the welfare system in Germany is fundamentally more fragmented than in Switzerland. While in Switzerland, support for reintegration is provided exclusively by the disability insurance (IV), in Germany there are various cost bearers (SGBs), which can potentially lead to more gaps in the care system. However, the study did not focus on differences in the care systems. Comparisons between Germany and Switzerland with regard to different interventions and concepts can be found in various places in the literature (25, 26). Nevertheless, this could also account for the differences in the distribution of diagnoses, the significantly smaller group with an F2 disorder in our sample (8% versus 24%) with strong similarity in the two hospitals for the other diagnostic groups. Mental comorbidities were significantly higher in our survey (67% versus 48%). The high proportion of psychiatric comorbidity is remarkable, as somatic comorbidities were still excluded. The issue of work was considered relevant for almost all young adults. However, an increased need for support especially among young adults and first-time sufferers could not be identified in our study.

With regard to potential differences in the population of the two healthcare service areas, the average unemployment rate in Germany at 5.3% (27) in 2022 was only slightly higher than in Switzerland at 4.3% (28) in the same year and does not explain the significantly higher number of unemployed people with a mental illness, mentioned by the study in Germany (13). However, the different poverty quotient in the two coverage areas of the two studies differ significantly, which limits comparability. For the urban coverage area of the survey in Germany, Berlin in the district of Friedrichshain-Kreuzberg, a poverty rate of 19.7% (29) is given. In densely populated areas of German-speaking Switzerland, on the other hand, the poverty rate is assumed to be 10.9% (30). As mentioned at the beginning, mental illness, poverty and the ability to work are closely linked. It could also be argued that the label "university" of the psychiatric clinic in our study has a positive influence on expectations regarding support for work integration. Even though the clinic in Germany, Berlin, the *Vivantes Klinikum am Urban*, is also an academic teaching hospital of the *Charité - Universitätsmedizin Berlin*, the label is less obvious and therefore the influence could be smaller. However, this cannot be investigated with our data, but should be considered for future studies.

The interest in participating in job coaching was also very high in our survey. This is an important prerequisite for implementing evidence-based approaches to (re)integration, such as "Individual Placement and Support" (IPS), i.e., direct entry into the first labor market with individual and long-term support (31). Contrary to the study in Germany (13), some of the patients surveyed in our sample were being treated in private wards (n = 10). It is known that people with private or semi-private insurance in Switzerland have a higher salary, higher education and are older than people with general insurance (32). As a result, it can be hypothesized that their work situation and requirements differ systematically. However, it must be borne in mind that (semi-)privately insured persons in Switzerland are not such an exclusive group at 29% (32). Our data shows that although the group with privately insured patients are on average more likely to have a job (60% versus 51%), the need for support is similar to that of the public/general departments (80% versus 76%).

What was striking and deviating from the results of the Berlin study (13) was the diagnosis-specific evaluation in our survey, especially for those with a main diagnosis from the field of personality and behavioral disorders. For these patients, the topic of work was addressed significantly more often than for the other diagnostic groups. At the same time, these patients expressed less need for help than the other diagnostic groups and only about half of them stated that they were offered support. In addition to a diagnosis-specific interpretation, the reasons for this could also lie in department-typical processes and structures. For the comparison with the results of the other diagnoses, it must also be considered that the F1 diagnoses were overrepresented (see Table 1). In any case, it became clear that despite a routine thematisation (91%) of the work-related participation situation, the need for support may be insufficiently covered. In this context, it was also noticeable that especially patients with work and first-time hospitalized persons were addressed on the topic of work, but patients without work and multiple hospitalized persons also expressed a high need for support. The current practice thus bears the risk of not providing sufficient care for patients who have already fallen out of work or chronically ill persons, since the topic of work is not sufficiently addressed in this group. However, it could be that for patients in a particularly precarious situation, topics such as housing and crisis management may have priority and the topic of work is therefore only taken up in a more stable situation. The results show that the discussion of work increases with the length of stay.

It was also found that patients who were in employment or had a training place as well as older patients expressed more concerns about (re) starting their training or job. Possible reasons for this were uncertainty as to whether these patients would be able to resume their activities after the inpatient stay or whether retirement would become necessary. Whereas for those without a job or training place, in some cases a pension had already been taken and this possibly led to fewer worries due to the clarified situation (excluded from the general labor market). Addressing concerns about the loss of a job or training place at an early stage and taking appropriate measures can not only lead to an increase in patient satisfaction, but job retention is also associated with less effort and better prospects of success for long-term employment in the first labor market than is the case with reintegration after job loss (19).

The finding that people with higher education are more likely to be employed in the labor market was confirmed. In addition, education and migration did not show any systematic differences with regard to the thematisation of work or the need for support.

The present study was able to show that work and training are highly relevant for people with a mental disorder and that there is a great interest in (re)entering employment in the primary labor market. Against the background of an increase in mentally related retirements in Switzerland in recent years (17), the urgency of routinely addressing work and training in the context of psychiatric treatment and providing assistance to discuss and initiate appropriate measures to support work and professional employment as early as possible (18) becomes all the more clear. Evidence-based programs of Supported Employment such as the most clearly described and most frequently evaluated is the IPS model. It offers promising evidence to reduce barriers to access to the world of work for patients with mental illness and to promote inclusion and recovery (7, 33). The core principles of IPS include rapid placement in the primary labor market, systematic development in the workplace, consideration of individual preferences, integration of mental health and employment services, and support from specialized services (34). Studies suggest that IPS can double the chances of permanent employment in the primary labor market (30, 33, 34). However, due to the difficulty of finding a suitable job in the first place, IPS approaches combined with skills training around job search and retention, such as social skills training (35, 36) or cognitive remediation training (37), are proving most effective. To this end, adjustments to the Swiss social security system would also be beneficial by allowing part-time work of less than 50% in the first labor market with a simultaneous IV pension (38). Although Switzerland has a very well-developed vocational training system, particularly with regard to the combination of training and work, the labor market results for low-skilled workers are poor (8). This also affects people who often suffer from a mental disorder. The relatively high full and extraordinary IV pensions are not beneficial to entering the labor market due to lack of incentives. There may be people for whom the primary labor market is not the right place since they are dependent on protection, despite integration measures (39). Also, the barriers to accessing a sheltered job are lower in Switzerland than in Germany (meeting the criteria for an IV pension is sufficient in Switzerland). However, sheltered jobs are often associated with lower income, less social integration and low professional prestige (40). In this regard, there is certainly a need to upgrade and adapt sheltered jobs too.

Ultimately, against the backdrop of the sharp rise in healthcare costs in Switzerland and the significant undersupply of mentally ill people in Switzerland (41) it is becoming increasingly clear how important it is to implement the most effective concepts in practice.

Limitations and future research needs

The survey collected the subjective patient perspective. A general discussion of the results with the treatment team was implemented, but a systematic study with the comparison of the patients' and the treatment team's perspectives would be exciting to uncover discrepancies, especially in the perception of support, and at best to show reasons for a lack of discussion of work. It remains open, for example, how patients define the help they receive from the treatment team. Consequently, it is possible that the patients did not perceive help as such from the treatment team's point of view. For future surveys, we recommend a prior definition of assistance for all survey participants. Furthermore, the sample is slightly biased with regard to age and diagnosis, which can be explained by the voluntary nature of the survey. A routine survey in the context of treatment could increase the representativeness of the population. It also remains open which influencing factors of the different care systems (Basel, Switzerland and Berlin, Germany) have caused the partially discrepant results in the comparison.

Consequences for clinical practice

The issue of work should be addressed in treatment regardless of age, diagnosis, frequency of hospitalization and place of work/training.

Measures are needed to minimize the expressed discrepancy between desired support and effective assistance through appropriate interventions.

Patients express great interest in evidence-based support for work-related participation such as Individual Placement and Support (IPS), i.e., job coaching with direct entry into the primary labor market. In practice, these programs should be increasingly implemented.

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 humans were approved by Ethics Committee Northwestern and Central Switzerland (EKNZ). The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and institutional requirements. 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

NH, LI, BH, and AN: substantial contributions to the conception and design of the work, and the acquisition, analysis, and interpretation of data for the work. DJ, and CH: revising the article critically for important intellectual content. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1232148/full#supplementary-material

References

1. Holinger B, Schoppmann S. Die Bedeutung von Arbeit für die persönliche recovery von psychisch schwer erkrankten Menschen. *Schweiz Z Psychiatr Neurol.* (2021) 11:8–11.

2. Riedel-Heller S, Stengler K, Seidler A. Psychische Gesundheit und Arbeit. *Psychiatr Prax.* (2012) 39:103–5. doi: 10.1055/s-0032-1304894

3. Schuler D, Tuch A, Peter C. Psychische Gesundheit in der Schweiz. (2020). Available at:https://dam-api.bfs.admin.ch/hub/api/dam/assets/15084053/master

4. Stöbel-Richter Y, Brähler E, Zenger M. Arbeitslosigkeit, psychische Belastung und körperliche Beschwerden – Ergebnisse einer Repräsentativerhebung. *Das Gesundheit.* (2011) 73:1283650. doi: 10.1055/s-0031-1283650

5. Weber A, Hörmann G, Heipertz W. Arbeitslosigkeit und Gesundheit aus sozialmedizinischer Sicht. *Dtsch Arztebl.* (2007) 104:2957–62. doi: 10.3238/arztebl.2008.0127a

6. Herbig B, Dragano N, Angerer P. Health in the long-term unemployed. *Dtsch Arztebl Int.* (2013) 110:413–9. doi: 10.3238/arztebl.2013.0413

7. Richter D, Hoffmann H. Effectiveness of supported employment in non-trial routine implementation: systematic review and meta-analysis. *Soc Psychiatry Psychiatr Epidemiol.* (2019) 54:525–31. doi: 10.1007/s00127-018-1577-z

8. OECD. *Psychische Gesundheit und Beschäftigung: Schweiz*. Bern: FSIO (2014).

9. Paul K, Zechmann A, Moser K. Psychische Folgen von Arbeitsplatzverlust und Arbeitslosigkeit. *WSI-Mitteilungen.* (2016) 69:373–80. doi: 10.5771/0342-300X-2016-5-373

10. Kuntz B. Bildung und Gesundheit In: T Schott and C Hornberg, editors. *Die Gesellschaft und ihre Gesundheit. 20 Jahre Public Health in Deutschland: Bilanz und Ausblick einer Wissenschaft*. Wiesbaden: VS Verlag für Sozialwissenschaften (2011)

11. Rabenberg M. Schwerpunktbericht der Gesundheitsberichterstattung des Bundes-Migration und Gesundheit. (2013); Available at:http://www.gbe-bund.de/pdf/migration.pdf

12. Marwaha S, Johnson S. Schizophrenia and employment - a review. *Soc Psychiatry Psychiatr Epidemiol.* (2004) 39:337–49. doi: 10.1007/s00127-004-0762-4

13. Jäckel D, Siebert S, Baumgardt J, Leopold K, Bechdolf A. Patients' work-related participation impairments and need for support in day hospital and inpatient psychiatric treatment. *Psychiatr Prax.* (2020) 47:235–41. doi: 10.1055/a-1112-5519

14. Knaeps J, Neyens I, van Weeghel J, van Audenhove C. Perspectives of hospitalized patients with mental disorders and their clinicians on vocational goals, barriers, and steps to overcome barriers. *J Ment Health.* (2015) 24:196–201. doi: 10.3109/09638237.2015.1036972

15. Mernyi L, Hölzle P, Hamann J. Berufstätigkeit und Rückkehr an den Arbeitsplatz bei stationärpsychiatrisch behandelten Patienten TT-Psychiatric inpatient treatment and return to work. *Psychiatr Prax.* (2018) 45:197–205. doi: 10.1055/s-0043-101901

16. Riedl L, Blank D, Kohl M, Lang A, Kehl V, Brieger P, et al. Return-to-work-experts for inpatient treatment of patients with mental illnesses– a proof-of-concept-study (RETURN): the study protocol. *BMC Psychiatry.* (2020) 20:177. doi: 10.1186/s12888-020-02504-4

17. Die Zukunft der Psychiatrie in der Schweiz. *Bericht in Erfüllung des Postulats von Philipp Stähelin*. Bern: Bundesamt für Gesundheit (2016).

18. Bundesamt für Sozialversicherungen. *Statistiken zur sozialen Sicherheit IV-Statistik*. (2022): Bundesamt für Sozialversicherungen. Bern. 1–11.

19. Hoffmann H, Jäckel D. Frührehabilitation -ein Stiefkind der Psychiatrie. *Psychiatr Prax.* (2015) 42:235–6. doi: 10.1055/s-0034-1387694

20. Zürcher SJ, Zürcher M, Burkhalter M, Richter D. Job retention and reintegration in people with mental health problems: a descriptive evaluation of supported employment routine programs. *Adm Policy Ment Health.* (2022) 50:128–36. doi: 10.1007/s10488-022-01227-w

21. Gühne U, Stein J, Schwarzbach M, Riedel-Heller S. Der Stellenwert von Arbeit und beruflicher Beschäftigung in der Behandlung psychisch kranker Menschen. *Psychother Psychosom Med Psychol.* (2017) 67:457–64. doi: 10.1055/s-0043-104855

22. Gühne U, Weinmann S, Riedel-Heller SG, Becker T. *S3-Leitlinie Psychosoziale Therapien bei schweren psychischen Erkrankungen*. Berlin: Springer (2019).

23. Bond GR, Peterson AE, Becker DR, Drake RE. Validation of the revised individual placement and support Fidelity scale (IPS-25). *Psychiatr Serv.* (2012) 63:758–63. doi: 10.1176/appi.ps.201100476

24. Cohen J. A power primer. *Psychol Bull.* (1992) 112:155–159. doi: 10.1037//0033-2909.112.1.155

25. Bechdolf A, Bühling-Schindowski F, Nikolaidis K, Kleinschmidt M, Weinmann S, Baumgardt J. Evidenz zu aufsuchender Behandlung bei menschen mit psychischen Störungen in Deutschland, Österreich und der Schweiz – eine systematische ÜbersichtsarbeitEvidence on the effects of crisis resolution teams, home treatment and assertive outreach for people with mental disorders in Germany, Austria and Switzerland – a systematic review. *Nervenarzt.* (2021) 93:488–98. doi: 10.1007/s00115-021-01143-8

26. Knapp M, Patel A, Curran C, Latimer E, Catty J, Becker T, et al. Supported employment: cost-effectiveness across six European sites. *World Psychiatry.* (2013) 12:60–8. doi: 10.1002/wps.20017

27. Statistisches Bundesamt (Deutschland), DESTATIS. Arbeitslosenquote Deutschland. (2023). Available at:https://www.destatis.de/DE/Themen/Wirtschaft/Konjunkturindikatoren/Arbeitsmarkt/arb210a.html?nn=213544

28. Bundesamt für Statistik (Schweiz). Erwerbslosenquote gemäss ILO nach Geschlecht, Nationalität und Altersgruppen, brutto-und saisonbereinigte Werte. Durchschnittliche Monats-, Quartals-und Jahreswerte. (2023). Available at:https://www.bfs.admin.ch/asset/de/28245741

29. Statistik. Amt für Statistik Berlin-Brandenburg. Mikrozensus 2016. (2017). Available at:www.statistik-berlin-brandenburg.de

30. Bundesamt für Statistik (Schweiz). Armutsquote, nach verschiedenen Merkmalen. (2023). Available at:https://www.bfs.admin.ch/asset/de/24205291

31. Drake RE, Bond GR, Becker DR. *Individual placement and support: an evidence-based approach to supported employment*. New York: Oxford University Press (2012).

32. Roth S, Zufferey J, Pellegrini S. *Personen mit und ohne Spitalzusatzversicherung: Vergleich der soziodemografischen Merkmale, des Gesundheitszustands und der Inanspruchnahme von Versorgungsleistungen Obsan Bulletin 2/2021*. Neuchâtel: Schweizerisches Gesundheitsobservatorium (2021).

33. Suijkerbuijk YB, Schaafsma FG, van Mechelen JC, Ojajärvi A, Corbière M, Anema JR. Interventions for obtaining and maintaining employment in adults with severe mental illness, a network meta-analysis. *Cochrane Database Syst Rev.* (2017) 2017:CD011867. doi: 10.1002/14651858.CD011867.pub2

34. Modini M, Tan L, Brinchmann B, Wang M-J, Killackey E, Glozier N, et al. Supported employment for people with severe mental illness: systematic review and meta-analysis of the international evidence. *Br J Psychiatry.* (2016) 209:14–22. doi: 10.1192/bjp.bp.115.165092

35. Tsang HWH, Fung KMT, Leung AY, Li SMY. Three year follow-up study of an integrated supported employment for individuals with severe mental illness. *Aust N Z J Psychiatr.* (2010) 44:49–58. doi: 10.3109/00048670903393613

36. Au DW, Tsang HW, So WW, Bell MD, Cheung V, Yiu MGC, et al. Effects of integrated supported employment plus cognitive remediation training for people with schizophrenia and schizoaffective disorders. *Schizophr Res.* (2015) 166:297–303. doi: 10.1016/j.schres.2015.05.013

37. McGurk SR, Mueser KT, Feldman K M.A., Wolfe R M.S., Pascaris A M.S., M.P. Cognitive training for supported employment: 2-3 year outcomes of a randomized controlled trial. *Am J Psychiatry.* (2007) 164:437–41. doi: 10.1176/ajp.2007.164.3.437

38. Hoffmann H, Richter D. Supported employment in Switzerland-are we on track? *Psychiatr Rehabil J.* (2020) 43:72–5. doi: 10.1037/prj0000400

39. Hoffmann H. Eingliederung statt ausgrenzung: supported employment und die 5. *Soz Sicher.* (2005) 1:37–40.

40. Hassler B. Geschützte Arbeitsplätze und Eingliederungsmanagement. In: Geisen T, Mösch P. (eds). *Praxishandbuch Eingliederungsmanagement. Springer Reference Sozialwissenschaften*. Wiesbaden: Springer; (2017).

41. Stocker D, Stettler P, Jäggi J, et al. *Versorgungssituation psychisch erkrankter Personen in der Schweiz*. Bern: Bundesamt für Gesundheit (2016).

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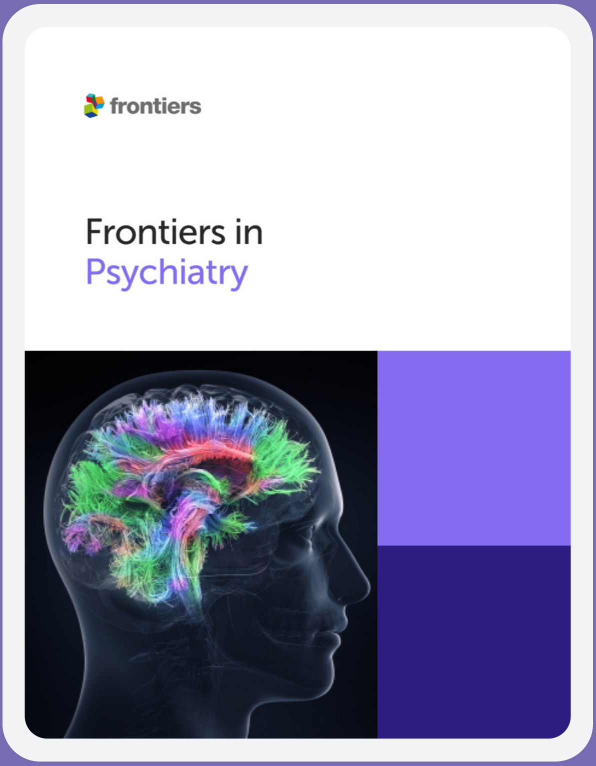

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