Research Topics

Situating phenomenological psychopathology: Subjective experience within the world

Edited by
Elizabeth Pienkos, Jasper Feyaerts, Rosa Ritunnano,
Jérôme Englebert and Louis Sass

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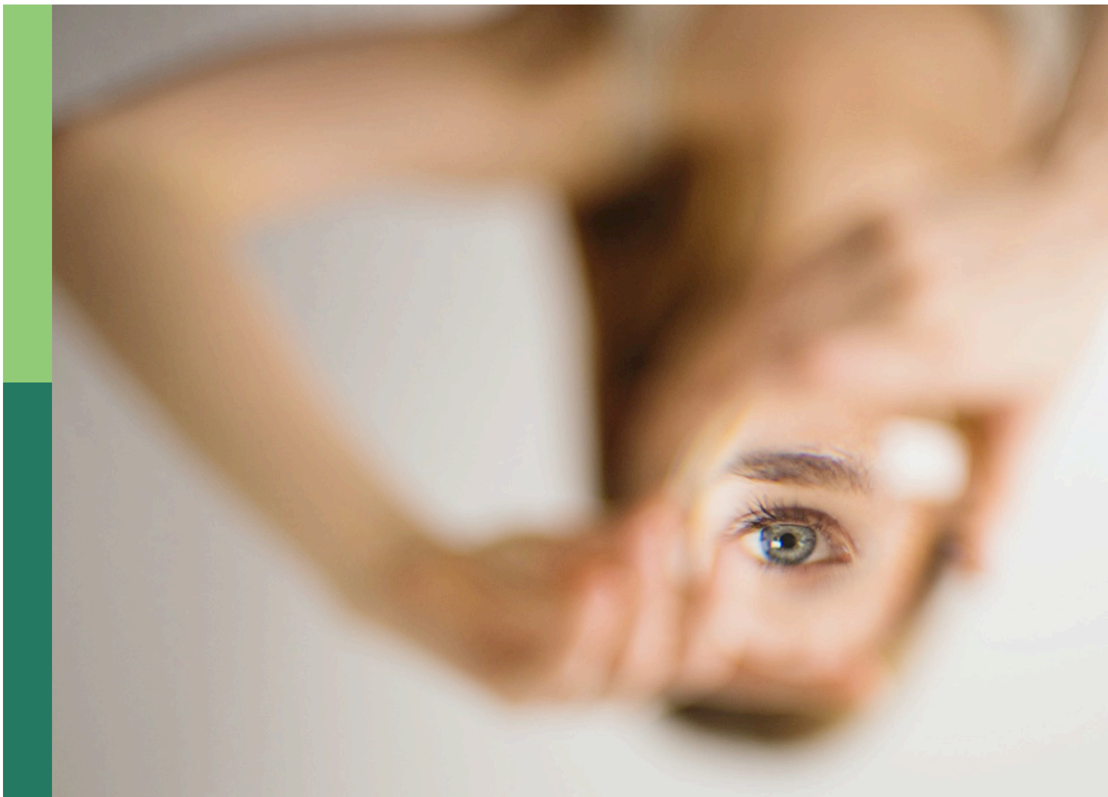

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Situating phenomenological psychopathology: Subjective experience within the world

Topic editors
Elizabeth Pienkos — Duquesne University, United States
Jasper Feyaerts — Ghent University, Belgium
Rosa Ritunnano — University of Birmingham, United Kingdom
Jérôme Englebert — Université libre de Bruxelles, Belgium
Louis Sass — Rutgers, The State University of New Jersey - Busch Campus, United States

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Table of contents

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Arieh Y. Shalev,
NYU Langone Health, United States

*CORRESPONDENCE
Elizabeth Pienkos
✉ pienkose@duq.edu

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Editorial: Situating phenomenological psychopathology: subjective experience within the world

Elizabeth Pienkos[1]*, Jérôme Englebert[2,3], Jasper Feyaerts[4], Rosa Ritunnano[5,6] and Louis Sass[4,7]

[1]Department of Psychology, Duquesne University, Pittsburgh, PA, United States, [2]Centre de recherche interdisciplinaire sur la déviance et la pénalité, Université Catholique de Louvain, Louvain-la-Neuve, Walloon Brabant, Belgium, [3]Centre de recherches pénalité, sécurité et déviances (CRPSD), Université Libre de Bruxelles, Brussels, Belgium, [4]Department of Psychoanalysis and Clinical Consulting, Faculty of Psychology and Educational Sciences, Ghent University, Ghent, East Flanders, Belgium, [5]Centre for Youth Mental Health, Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne, Parkville, VIC, Australia, [6]Institute for Mental Health, School of Psychology, University of Birmingham, Birmingham, United Kingdom, [7]Graduate School of Applied and Professional Psychology, Rutgers, The State University of New Jersey, Piscataway, NJ, United States

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Editorial on the Research Topic
Situating phenomenological psychopathology: subjective experience within the world

Introduction

The field of phenomenological psychopathology was originally developed in the early 20th century. It has seen a recent resurgence, largely heralded by Sass and Parnas's (2003) influential ipseity disturbance model of schizophrenia. Throughout its history, this field has represented an important counter-trend to biomedical approaches to psychiatry, placing subjectivity at the forefront of psychopathological research (Parnas et al., 2013).

Several recent works have indicated the beginning of a shift in the emphasis of phenomenological psychopathology, broadening the view of subjectivity as extended and embedded in a social, cultural, and historical world. Such a move may be found in expanded models of schizophrenia (e.g., Sass et al., 2018; Englebert, 2021), attention to the personal and cultural meanings of symptoms (e.g., Feyaerts et al., 2021; Ritunnano, 2022), and greater focus on life historical and cultural events in phenomenological research (e.g., Van Duppen and Feyaerts, 2021; Pienkos, 2022).

With this Research Topic, we hope to mark the beginning of a ***situated phenomenological psychopathology***—an approach to studying mental disorders that explicitly recognizes the intertwining of self and world in subjective experience. The papers that have been included here reflect the current state of research and simultaneously point toward possibilities for future inquiry. They focus on a variety of mental or emotional disorders, including depressive disorders, body dysmorphic disorder, autism spectrum disorder, substance misuse, and contemporary manifestations of "hysteria," as well as schizophrenia. We view the authors as raising and responding to several important questions that indicate the way forward for this situated phenomenology, which we summarize here.

What is the relationship between psychiatric disorders and experiences of the external world?

Osler adds important nuance to characterizations of interpersonal experience in depression, finding that difficulties in shared "we-experiences" heighten the sense of aloneness, alienation, and difference in depressed individuals. Lindhardt et al. offer novel empirical data on the psychopathology of youth not in education, employment or training, finding that this population has been critically overlooked and is a candidate for prevention and early intervention strategies in schizophrenia-spectrum disorders. A previously unpublished case study by Erwin Straus, originally written in 1946 and introduced here by Moskalewicz and Fuchs, describes transformations of lived time and space in a case of severe depression, and how these are meaningfully linked with the patient's felt relationship to the world. These papers develop our understanding of the circular relationship between an individual and their interpersonal and practical world, and offer a glimpse of how this world of social and pragmatic interchanges may be engaged to modify the experiences of people with depression or schizophrenia.

How are our diagnostic categories and criteria embedded in the world?

Mancini et al. argue that the diagnostic categories associated with "hysteria" are replete with historical and cultural assumptions, even in the contemporary manifestations of histrionic personality disorder and conversion disorder. This has had the effect of essentializing contingent symptoms of hysteria, historically resulting in over-diagnosis in women and an over-emphasis on sexuality. To remedy this, the authors advocate for searching for a homogeneous subjective core that is understood in the context of patients' lifeworlds, one that seeks recognition and the establishment of selfhood via the gaze of the other. Such a critique might push us to question the cultural contingencies of other disorders, including symptom manifestations, diagnostic criteria, and conceptualizations.

What paradigms and methods are best suited to explore the relationship between self and world in psychopathology?

Boldsen uses phenomenological and ethnographic methods to explore the overwhelming and unpredictable sensory dimensions of interpersonal experience in autism. She finds that what are often viewed as pathological behaviors instead represent important "styles of being" that enable people with autism to navigate their worlds. Messas and Fernandez note that while phenomenological psychopathology has been fruitfully applied to understanding and explaining schizophrenia, the field's shift to incorporate the context of illness should also involve a shift in paradigm case. The particular relevance of the social and cultural context in which substance misuse occurs make it especially apt for demonstrating the value and methods of a contextual or situated phenomenology.

How do world events impact the progression and amelioration of psychopathology?

Craythorne et al. use Interpretative Phenomenological Analysis to give voice to the often-neglected perspective of those living with Body Dysmorphic Disorder. They locate the roots of the disorder within enduring experiences of inter-personal rejection, shame and self-other discrepancy. Medford and Sigala's case study of a Huntington's patient with delusions of lycanthropy indicate the importance of understanding and addressing a patient's life history in the development of anomalous expressions of distress, even in illnesses that have entirely neurological origins. Irarrázaval and Kalawski investigate the role of emotional disruption in the development of psychopathology, finding that the empathic communication of psychotherapy can alter emotional experiencing and result in increased capacity for empathy. Vescey et al.'s study employs participatory action research to explore member experiences of a psychosocial clubhouse, showing how the recovery process is facilitated through enhancing agency and meaningful activity, and indicating that participatory methods can challenge assumptions embedded in models of psychopathology. These papers find that interactions in the world are not only impacted by psychopathology, but are also indispensable for understanding the development of psychopathology and recovery from it.

Conclusions

These articles forcefully respond to the Research Topic while also opening up new lines of applied phenomenological research. We see the need for a different kind of sensitivity to the worldly context or situation in which psychopathology is embedded, requiring methodological development, expansion and cross-fertilization of disciplines. Researchers are called to situate their enquiries within particular, historically-grounded, and contextually-bounded lifeworlds. This collection also illustrates how attention to the environment may lead to a partial reconsideration of the psychopathological experience in a less strictly maladaptive or abnormal framework, but as the creation of new norms of existence in interaction within the world. If this approach is to take hold, it will be through the commitment of researchers to asking contextually-sensitive questions, attending to and modifying the limitations of current research methods, and remaining open to the novel and transformative insights that emerge from their work.

Author contributions

EP prepared the main manuscript. JE, JF, RR, and LS provided additional content and editing.

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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ORIGINAL RESEARCH
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Autism and the Sensory Disruption of Social Experience

*Sofie Boldsen**

Department of People and Technology, Roskilde University, Roskilde, Denmark

Autism research has recently witnessed an embodied turn. In response to the cognitivist approaches dominating the field, phenomenological scholars have suggested a reconceptualization of autism as a disorder of embodied intersubjectivity. Part of this interest in autistic embodiment concerns the role of sensory differences, which have recently been added to the diagnostic criteria of autism. While research suggests that sensory differences are implicated in a wide array of autistic social difficulties, it has not yet been explored how sensory and social experience in autism relate on a phenomenological level. Given the importance of the sensory dimension of social encounters in phenomenological analyses of autism, this question must be considered crucial. This article investigates the role played by sensory differences in autistic social experience. Through a phenomenological analysis informed primarily by the philosophy of Maurice Merleau-Ponty with particular emphasis on the relation between intersubjectivity and perception, I argue that sensory differences affect the way other people appear in autistic experience on a pre-reflective level. By drawing on autistic young adults' experiential descriptions of social encounters, this article identifies three aspects of how sensory differences affect social experiences in autism. First, social encounters manifested as sensorially disturbing, chaotic, and unpredictable events. Second, the embodied expressions of others appeared unfamiliar, threatening, and promoted a sense of detachment from the social world. Third, deliberate practices were employed to actively seek perceptual and social meaning in these disorienting social encounters. This analysis stresses the importance of understanding embodied intersubjectivity through its sensory dimensions. In addition, it indicates an important avenue for future research in exploring the potential role of practice in maintaining an intuitive grip on social meaning. By approaching social encounters as sensory and perceptual events, I emphasize how social difficulties in autism are inherently world-involving phenomena rather than a cognitive deficit reducible to the autistic person.

Keywords: autism, qualitative research, sensory differences, social interaction, embodiment, phenomenology

Edited by:
Louis Sass,
Rutgers, The State University of New Jersey - Busch Campus, United States

Reviewed by:
Timothy J. Beck,
Landmark College, United States
Nicolás Alessandroni,
Concordia University, Canada

Correspondence:
Sofie Boldsen
boldsen@ruc.dk

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INTRODUCTION

Autism is a developmental disorder characterized by pervasive difficulties with social communication and interaction and restricted, repetitive interests and behaviors (Kanner, 1943; Asperger, 1991; American Psychiatric Association, 2013; World Health Organization, 2018). Since the 1980s, the paradigm of theory of mind has retained a dominant position in autism research and described social difficulties in autism as results of a failed maturation of the cognitive system arguably responsible for our ability to infer the mental states of others (Baron-Cohen et al., 1985). Apart from the theory of mind hypothesis, major theories of autism include the executive dysfunction theory, according to which autistic persons have a weakened ability to manage their cognitive processes (Ozonoff et al., 1991), and the weak central coherence theory, which focuses on a detail-oriented processing style as compromising the ability of autistic persons to process global and contextual information (Happe and Frith, 2006). Despite their differences, these major theories represent an approach to autism focused on cognitive functioning. One prominent idea in the theory of mind literature is that autistic persons lack access not only to others mental states' but also to their own (Frith and Happe, 1999). Following such a framework, it makes little sense to explore subjective experience in autism, and as has been argued, autism research has historically not paid much attention to and even discredited autistic accounts of their own experiences (McGeer, 2005; Milton, 2014b; Botha, 2021). The starting point of this article is the assumption that the most important source of knowledge about autism is the experiences and perspectives of autistic persons.[1] For years, autistic persons have been pushing for an acknowledgment and understanding of sensory and bodily aspects of autism, which have been neglected in a paradigm where the cognitive machinery is assumed to constitute the essence of autism [see Milton (2014a); Leong (2016) and Walker (2019)].[2]

Based on a recognition of subjectivity and embodiment in autism, emerging phenomenological approaches have also objected to the predominantly cognitive paradigm in autism research and suggested a reconceptualization of autism as a disorder of embodied intersubjectivity rather than higher-order cognitive processes (Gallagher, 2004; Zahavi, 2005; Fuchs, 2015; Krueger, 2021). As argued by Thomas Fuchs, "what autistic children primarily lack is not a theoretical concept of other minds but a primary sensus communis or a sense of bodily being-with-others" (Fuchs, 2015, p: 198). Indeed, autism research has witnessed an embodied turn, partially precipitated by a growing body of empirical research demonstrating the role of pervasive sensorimotor differences in the development and manifestation of autism (Hobson, 2002; Fournier et al., 2010; Donnellan et al., 2013; Eigsti, 2013; Robertson and Baron-Cohen, 2017).[3]

Part of this increased orientation toward bodily processes in autism is a renewed interest in sensory differences, which were recognized already in the early years of autism research (Kanner, 1943; Hutt et al., 1964; Hermelin and O'Connor, 1970; Ornitz, 1974). Despite having been largely forgotten as the history of autism research progressed, recent research suggests that sensory differences occur in over 90% of autistic individuals and impact fundamental areas of functioning, such as perception, action, engagement in everyday activities, and social interaction (Leekam et al., 2007; Baranek et al., 2008; Robertson and Baron-Cohen, 2017). In addition, the autism literature suggests that sensory differences are implicated in a wide array of social difficulties in autism (Woynaroski et al., 2013; Dakopolos and Jahromi, 2019; Kuno-Fujita et al., 2020; Lin, 2020). Autistic self-reports have highlighted the importance of subtle and pervasive sensory differences for understanding social difficulties (Cesaroni and Garber, 1991; Williams, 1992; Hale and Hale, 1999; Biklen, 2005; Grandin, 2006). For example, a 13-year-old boy, "Albert," describes being overstimulated by touch, reporting that "it hurts" and "it's too much," causing him to stiffen up in situations involving physical contact (Cesaroni and Garber, 1991, p: 306–307). Autistic writer and artist Donna Williams explained how sensory differences affected her ability to process information through multiple sensory modalities, causing her to "turn off her ears" if she needed to maintain eye contact (Williams, 1992). While such issues undoubtedly affect social engagement in autism, the question remains of how to characterize this process further and how to understand it on an experiential and phenomenological level.

This article aims to clarify the relationship between sensory and social experience in autism by exploring how the embodied expressions of other people in social contexts appear in autistic sensory experience. Given the importance granted to the sensory and perceptual dimension of social encounters by phenomenological accounts of autism, this question must be considered crucial. To shed light on this question, I draw on qualitative data from an ongoing research project on autistic social experience and practice gathered through extensive fieldwork in social groups for adolescents and young adults with autism and in-depth qualitative interviews with the group participants.

Through a phenomenological analysis informed primarily by the philosophy of Maurice Merleau-Ponty, I argue that sensory differences affect the way other people appear in autistic experience on a pre-reflective level. By exploring the diverse ways in which sensory differences can destabilize the experience of social encounters, this article points to the importance of understanding the sensory dimensions of embodied intersubjectivity and the potential role of practice and activity in the experience of social

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[1] Part of this starting point is also embracing identity-first language to acknowledge how autism is increasingly being understood by those diagnosed with autism as an integral part of one's identity and being rather than reproducing problematic assumptions of autism as a curable disease or error to be corrected (Vivanti, 2020; Botha et al., 2021). Although person-first language usually intends to emphasize the value and humanity of the person, in the autism community and disability movement, it is often taken to imply that "autism is entirely separate from what gives him or her value and worth," and ultimately that "it would have been better if he or she had been born typical" (Brown, 2011).

[2] One aspect of this push for recognition is the autism community's movement toward the reappropriation of autistic bodily expressions, such as repetitive movements and self-stimulatory behaviors ("stimming"), which historically have been depicted from a behaviorist perspective as something to be eliminated (Boyd et al., 2012).

[3] The advent of these embodied and phenomenological approaches to autism relates to a parallel movement in cognitive science, where second-person approaches are gathering momentum. By promoting the idea that social understanding emerges from and is conditioned by concrete and embodied interaction (de Jaegher and di Paolo, 2007; Schilbach et al., 2013; Ferrer de Luna, 2019), these approaches contribute to developing an embodied and relational approach to autism (Gallagher, 2004; de Jaegher, 2013, 2021).

meaning. By approaching social encounters as sensory and perceptual events, I emphasize how social difficulties in autism are closely related to the experience of the surrounding world and thus inherently world-involving phenomena rather than cognitive deficits reducible to the autistic person.

MATERIALS AND METHODS

Theoretical Background: Intersubjectivity and Perception in Merleau-Ponty

A central aspect of phenomenological accounts of autism is the attention to the embodied and perceptual nature of intersubjective encounters. Below, I will introduce a phenomenological understanding of the relation between intersubjectivity and perception, which will form the theoretical basis of the following analysis of sensory and social experience in autism. The phenomenological approach to social experience has much in common with more recently developed second-person approaches to social cognition and interaction, according to which social understanding proceeds directly in concrete interactional contexts without the need for inference or mental representation. Indeed, the Merleau-Pontian and Husserlian notion of the body has contributed significantly to developing enactive accounts of cognition (Gallagher, 2018; Bar, 2020). Despite this common ground, the following account will remain largely within the parameters of Merleau-Ponty's phenomenology to pursue and focus on the experiential and perceptual features of intersubjectivity rather than on the interactional dynamics themselves.

On a phenomenological account, social understanding and interaction are not processes mediated by reflective activity, as the experiential life of another person is present immediately in the form of bodily expressivity. According to Merleau-Ponty, observable behavior does not hide the other's emotions, intentions, thoughts, and desires as inaccessible internal states (Merleau-Ponty, 1964a, p: 52–53). Instead, they are embodied as meaningful expressions directly available in perceptual experience.[4] Social encounters are thus perceptual events, which Merleau-Ponty emphasizes through his description of the "esthesiological phase" of empathy:

> The whole riddle of Einfühlung lies in its initial, "esthesiological" phase; and it is solved there because it is a perception. He who "posits" the other man is a perceiving subject, the other person's body is a perceived thing, and the other person himself is "posited" as "perceiving." It is never a matter of anything but co-perception (Merleau-Ponty, 1964b, p: 170).

Drawing on Edmund Husserl's analysis of double sensation (Husserl, 1989), Merleau-Ponty argues that the experience of others is a perception in which the other's body appears not only as a perceived thing but a perceiving, sensing, living being. One perceives the other as perceiving, and consequently, the other appears in the form of a different sensibility and mode of perception.

Recently, Køster (2021) has drawn attention to this sensory dimension of intersubjectivity in his analysis of the felt sense of the other. For example, hearing the unique sound, melody, and tonality of the voice of a loved one or noticing their distinct scent or patterns of movement represents how the experience of others is sensory and affective rather than cognitive or epistemic. Drawing primarily on Merleau-Ponty, Køster describes the felt sense of the other as a sensorium, understood as an experiential structure constituted reciprocally by the other's expressive style and the perceiver's style of perceiving (Køster, 2021, p: 64).

The sensorium of the other thus denotes a complex phenomenological structure through which the other person appears "as a unified whole through a range of sensory modalities" (Køster, 2021, p: 58). Køster outlines the sensorium of the other as an inter-modal phenomenon through the ability of sensory modalities to "coalesce and manifest in highly intermodal and synesthetic ways" (Køster, 2021, p: 67). Køster's analysis aligns with Merleau-Ponty's understanding of social experience as revealing the other as a meaningful whole rather than a series of impressions. According to Merleau-Ponty, perception always transcends what is directly given in perception as the object as a totality always gives more than its intuitively given profiles. In the following, Merleau-Ponty describes how perception is thus co-constituted by the pre-reflective co-intention of a horizon of non-perceptions.

> The perceived is composed of lacunae that are not merely "non-perceptions." I can know that a crystal that I see or touch has a "uniform" shape without having, even tacitly, counted its sides. I can become familiar with a person's face without ever having perceived, for itself, the color of the eyes (Merleau-Ponty, 2012, p: 11).

Although the world is always given perspectivally rather than in its totality, objects appear in experience as meaningful wholes. According to Merleau-Ponty, "we hardly perceive any objects at all, just as we do not see the eyes of a familiar face, but rather its gaze and its expression" (Merleau-Ponty,

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[4] The view that mental states are directly available in perceptual experience bears on the idea that intentions and emotions are concretely embodied in expressive behavior. Seeing, hearing, or feeling another person's bodily expressions thus present their emotions or intentions directly, that is, without mediation from reflection, inference, or metarepresentation. This phenomenological understanding of perception and social experience has recently gained increased attention in 4E approaches to cognitive science under the heading "direct social perception" (Spaulding, 2015; Krueger, 2018). One potential challenge for such an approach to social cognition is accounting for how social interaction and understanding develop throughout life and become smoother with time. Here, it is fruitful to take a closer look at the idea of perception implied in this view. Perception is not a passive, observatory stance through which we receive and subsequently process sensory input. Rather, perception is inextricably tied to bodily activity. In the case of social perception, experiencing and understanding the other's expressive behavior is an interactive process. Thus, the complexity and nuance of social understanding develop and mature as social interaction also becomes more complex. For additional discussion, see Vincini and Gallagher (2021).

2012, p: 294). In this way, the experience of another person relies on only tacitly (rather than thematically) experiencing aspects such as facial features. Thus, perception of objects and people both rely on this oscillation between object and horizon that Merleau-Ponty characterizes as the "two-sided act" of perception.

> To see the object is to plunge into it and because objects form a system in which one object cannot appear without concealing others. More precisely, the inner horizon of an object cannot become an object without the surrounding objects becoming an horizon, and so vision is a two-sided act (Merleau-Ponty, 2012, p: 70).

Merleau-Ponty's idea of vision as a "plunging into" objects furthermore emphasizes how perception is active communication with, rather than something "exerted on," the world (Merleau-Ponty, 2012, p: 53). In their phenomenological analysis of the notion of sensus communis, Samuel Thoma and Thomas Fuchs emphasize how perception is a way of "sensing and touching the world, whereby the subject gets in close contact with what is sensed, moves towards it, and is moved by it" (Thoma and Fuchs, 2017, p: 139). This reciprocity of perception is perhaps most clearly expressed in the perception of another person, where we experience the encounter with another perspective on the world in which "a different comportment and a different gaze take possessions of my things" (Merleau-Ponty, 1964b, p: 170).

This understanding of the perceptual dimension of social encounters provides a sound theoretical framework for understanding how sensory differences affect social experience in autism through facilitating attention to the complex perceptual and bodily structures of our experience of other people. In the following analysis, I will focus primarily on Merleau-Ponty's notion of horizon and Køster's notion of the felt sense of the other as a conceptual basis for exploring the variety of ways autistic persons sense, feel, and handle social encounters.

Methodology

The following analysis draws on empirical data from an ongoing qualitative and phenomenological study exploring the pre-reflective and sensory aspects of social experience in autism and its connection to embodied and material practices. This phenomenological orientation warrants an approach to qualitative research adapted to how the phenomenon in focus expresses itself in experience (Boldsen, 2021). This study draws from resources from both descriptive phenomenological psychology (Giorgi, 2009; Englander, 2020; Englander and Morley, 2021), micro-phenomenology (Petitmengin, 2006), and interdisciplinary approaches to phenomenology and qualitative science (Høffding and Martiny, 2016; Ravn, 2021). The empirical context in which this study explored social experience and practice are social groups for young people with autism. These groups represent an increasingly popular approach to addressing social difficulties in autism by facilitating friendship between peers and providing social competence training.

This study employed an exploratory research design that combined ethnographic fieldwork and qualitative interviews within a phenomenological framework. Fieldwork spanned one and a half years, from October 2017 to June 2019, and included participant observation in two social groups for autistic adolescents and young adults hosted by a Danish autism center: one for autistic women aged 18–27 and one mixed-gender group for autistic young people aged 15–21. Observations at the biweekly group meetings were occasionally supplemented with day trips or sleepovers during weekends and after-meeting debriefings with the autism center staff. In addition, qualitative interviews were conducted from February 2019 to May 2019 with eleven group participants, seven from the youth group and four from the women's group, one interview per participant. The length of the interviews ranged from fifty to ninety minutes.

In two ways, fieldwork in the autism groups played a crucial role in supporting the qualitative interviews that formed the second part of this study's data collection. First, by providing access: As group participants tended to distrust psychologists and the possibility of evaluation, and because face-to-face interactions can feel unsafe for autistic individuals, prolonged fieldwork eased the process of building the interpersonal trust necessary to conduct qualitative interviews. Second, by refining the focus of interviews: Emerging familiarity with the group participants' experiences and social practices pointed to relevant topics to address in conversation and helped the interviewer's participation in the process of recalling and describing various experiences (Høffding and Martiny, 2016; Ravn, 2021).

A phenomenological approach to qualitative interviews was adopted to pursue experiential, pre-reflective, and sensory features of social engagement in autism. This approach drew inspiration from the interview techniques advocated by phenomenological psychology (Englander, 2020) and the micro-phenomenological interview (Petitmengin, 2006). Using qualitative interviews within a phenomenological framework requires the facilitation of experiential descriptions rather than explanations or opinions (Høffding and Martiny, 2016; Englander, 2020). This requirement was cashed out by focusing interview questions on concrete instances of social experience and working through its pre-reflective and sensory features (Petitmengin, 2006). A semi-structured interview guide was developed that focused on concrete social situations and the sensory, bodily, and material features constituting negative and positive social experiences. Many aspects of interviewing may be difficult for autistic persons. Social interaction with the interviewer may be experienced as overwhelming, verbalization of experiences and emotions may be difficult, and the interview situation itself may be stressful and anxiety-provoking. In addition, autistic persons express themselves in atypical ways, motivating some scholars to recommend visual aids during the interview (Shepherd, 2015). To accommodate such challenges, all interviews were conducted at the autism center during group nights to meet participants' need for stability and sense of security and minimize intervention into everyday life routines. Great care was taken to produce an autism-friendly interview situation. Interviewees were invited to engage in whatever activity they preferred, such as drawing, fidgeting, and listening to music during the interview to increase a sense of comfort in a potentially stressful situation. In addition, an employee from the autism center with whom interviewees felt safe was made available for debriefing after the interviewee if needed. After each interview and in dialogue with developing understandings of autistic social practices achieved during fieldwork, the interview guide was refined and specified as new aspects of social experience in autism emerged.

The analysis in this study aimed to explicate and describe the phenomenological structures underlying and supporting the autistic social practices and experiences documented in the data. This aim was reached through a method of analysis that employed both exploratory and phenomenological strategies divided into two stages. The first analytic stage sought to understand the lived experiences and practices expressed in the data on their own premises. This process was initiated by exploratorily reading and re-reading the data material, following Amedeo Giorgi's strategy (Giorgi, 2009). Through this initial immersion, codes were developed to organize data according to central aspects of participants' lived experiences of social interactions, such as "being overwhelmed by voices" or "disconnection from others." The second analytic stage described the phenomenological structures supporting the participants' lived experiences and practices. Two processes defined this stage. The practice of explicating latent or tacit meanings in the data (Englander and Morley, 2021) and exploring structural aspects of these meanings with inspiration from phenomenological analyses and concepts (Ravn, 2021). At this stage, the coding of the data aimed to connect participants' experiences with phenomenological themes reflecting the analytic interest of the researcher, such as "reciprocity" and "foreground and background in sensory experience." In the following presentation, data excerpts were selected according to their ability to exemplify core features of both analytic stages. Moreover, the presentation will reflect the process of moving from how participants describe and understand their own experiences to a discussion of the phenomenological structures underlying and supporting these experiences.

The Danish Committee System on Health Research Ethics reviewed the ethical dimensions of his study. Following the guidelines on research ethics in the social sciences and humanities provided by the European Commission, the following steps were taken to ensure the ethical integrity of this study (European Commission, 2018). First, informed consent was sought during fieldwork and at the time of interviewing, where gradually increased familiarity between researcher and research participants formed the basis of trust. All research participants and their parents, if underage, signed a written consent form. Second, data were treated following the EU General Data Protection Regulation [Regulation (EU) 2016/679 of the European Parliament and of the Council, 2016], pseudonyms for the research participants were used, and place names and other details enabling the identification of research participants were changed.

RESULTS

The Sound of Voices and the Texture of Skin

To describe how other people appear in autistic sensory experience, I will present a series of descriptions of social experiences provided by adolescents and young adults with autism during qualitative interviews. As described above, interviews addressed how research participants experience social interaction, why it can be challenging, and how they handle these challenges. As examples of socially challenging situations, participants described a wide range of social situations, such as family dinners, small talk with friends, encountering strangers, parties, or group exercises at school. A general feeling of being overwhelmed by and separated from others in social situations runs through these descriptions. One prominent feature of these experiences is their sensory manifestation. Participants usually described being overwhelmed as the uncomfortable sensory and affective experience of sound, touch, or visual aspects of the social environment appearing oppressive, chaotic, and threatening. In addition, social situations were described as intrusive and claustrophobic and as provoking a form of withdrawal or retreat from interactions with others and a sense of being separated from one's surroundings and other people.

Johanne, a 26-year-old woman with Asperger's Disorder, describes this feeling of being overwhelmed in a social setting through her experience of the buzzing soundscape of voices and conversations at a family gathering:

> It is like a constant blanket of sound that just keeps coming at you until you are totally disoriented. […] You cannot really get away, and it's like a sea, that just… It's just everywhere, and you cannot get away. […] I do not know if the sounds, in a way, are more penetrating… As if they are reaching a deeper layer of the psyche or that they do not just pass by.

Johanne describes the surrounding voices as a sea or a blanket of sound rushing over her in an invasive or penetrating manner. The social gathering she is part of appears sensorially dense and saturated to a point where the conversations around her do not consist of meaningful voices but dissolve into undecipherable noise. Nina, a 17-year-old woman with Asperger's Disorder, describes a similar experience of sensory saturation in a situation in which she is trying to have a conversation at a party:

> There were many people whirling around me, so there were a lot of impressions, also because I wanted to look at and hear and follow everything. […] It's like if you are trying to focus on something, and then there is someone in the periphery of your eyesight flicking their fingers [showing a flicking/fanning movement with the fingers beside her head], and it just will not stop. When I was sitting at a table talking to someone, then that was what those dancers that whirled around felt like. […] It's a bit like if someone is coming up behind you […] Almost

> as if you can feel someone's touch without them actually touching you.

Like Johanne, Nina describes how the sensory background of a social situation, here the movements of dancing people in her visual periphery, refuses to remain a tacit background and demands attention with acuteness and emergence. In Johanne's case, the auditory horizon of casual conversation around the table refused to remain a tacit background. Instead, it intensified and experientially 'thickened' until it was no longer background but an overwhelming 'sea' of noise. Simultaneously, everything and nothing are in focus, thus representing an imbalance between the thematized and the tacitly co-intended in perceptual experience. Nina's description of the peripheral whirling dancers elaborates on this imbalance. In this case, it seemed that the dancers' movements did not remain visually implicit but demanded attention as explicit objects and disturbed her experience of proximity and presence to the conversation in which she was engaged.

There is a sense in autistic social experience that various co-perceived aspects, such as gestures and movements in the background, or the acoustic qualities of a voice, lose their tacit and implicit character and surface in perception as thematized objects of attention. This implies a double movement. First, the usual background noise in the auditory and visual environments loses its character as an unnoticed background and instead moves to the foreground of experience. Second, the sense of presence in the concrete interaction dissolves into a sea of noise and movement. Thus, the perceptual saturation implied in the above descriptions indicates an experiential disconnection from the perceptual situation and its meaning.

What is described by Merleau-Ponty as the two-sided act of perception seems to manifest radically differently in these descriptions. Rather than the smooth oscillation between object and horizon that Merleau-Ponty describes, autistic social experience is described by Nina and Johanne as a perpetual foregrounding or coming-to-attention of the world. Rather than remaining a background upon which the embodied expressions of the other person can stand out as meaningful, the sensory surroundings are experienced as invasive and violently closing in. The idea of perception as a simultaneous sense of moving and being moved by the world is replaced by a sense of being pushed away by a sensorially chaotic, unpredictable, and unfamiliar world.

In another context, Nina describes the feeling of being overwhelmed by other people through the experience of touch in a situation where a stranger reaches out to shake her hand.

> It's a very panicked feeling. It's as if you are presented with a box in which you know there's something inside, and people want you to feel what it is. It's the same feeling of "ohhh no, something is there!" and you do not know what is in the box or what this sensation is going to feel like […] You do not really know what the person wants, just like you do not know what's in the box. Like in Diva's in the Jungle [Danish reality TV program, ed.] where they put a pig's heart or some chicken in there, and the participants have to stick their hands in there. You do not know what's in the box. Some people have very soft hands, some feel kind of rough, and some are almost a little wax-like as if their hands are greasy. […] So you do not know what is reaching for you, and you do not know what this person will do with your hand.

Like the descriptions recounted above, Nina communicates the feeling of being overwhelmed through the intense experience of sensory proximity. In the situation, she avoids reciprocating the stranger's gesture. Instead, her experience concerns the feeling of the hand approaching, closing in, and the preemption of what awaits when it finds her. Her anticipation of the hand's texture, its possible greasy, wax-like, rough, or soft qualities, engulfs her experience to a point where she cannot respond to the handshake as a meaningful gesture. In her experience, what approaches her is not a handshake but something she compares to raw meat. A shared feature of the descriptions of social situations addressed above is the sense of the sensory surroundings, whether buzzing voices, peripheral movements, or skin texture, closing in, approaching, and becoming experientially invasive.

In the examples recounted above, the experience of the other person as immediately meaningful, which both Husserl and Merleau-Ponty associated with most social encounters, seems to be obstructed by the overwhelming experience of the sensory features of the encounter, such as the texture of skin in Nina's case or the auditory quality of voices in Johanne's case. The constant surfacing of these material features of the other's body as thematic objects of attention renders the other alien and uncanny and amounts to a form of experiential noise or static that interferes with the possibility of social engagement. One might even say that sensory experience introduces a veil of perception that disrupts the immediacy with which the other person appears meaningful.

Furthermore, what permeates the experiences described above is their sensory-affective dimension—social situations and interactions present as chaotic and unpredictable and with a sense of oppressiveness and threat. For example, in the case of Nina's experience with the stranger, the handshake is experienced as a violent approach of something frightening and unexpected rather than a friendly gesture. Similarly, Johanne's experience of being engulfed by a sea of noise implied a strong sense of affective alienation from the social situation from which she experientially withdraws when social expectations make it difficult for her to leave physically. In her own words, "I can get so distant and almost isolated from what happens around me because I just shut down." Thus, sensory experience in autism can disrupt the sense of familiarity with others and the sense of security in social situations.

Familiarity and Alienation in Autistic Social Experience

According to Køster, the feeling of familiarity with other people is so fundamental to social experience that "like many phenomenologically interesting experiences, it may only become salient through its explicit absence" (Køster, 2021, p: 58). The following descriptions reveal such an absence by presenting experiences of social encounters in which a sense of alienness and opacity permeate the social situation and the other person. Moreover, they reveal how this felt sense of the other disturbs the possibility of social engagement by promoting affective withdrawal and disconnection.

Hanna, a 17-year-old woman with Asperger's Disorder, describes her response to a social situation, where the soundscape of the family gathering on Christmas Eve feels overwhelming and chaotic:

> It is like I'm beginning to shake uncontrollably and cannot sit still. I just want to get out of my body, although I cannot. No matter what I do, I cannot get calm. [Interviewer: And then what do you do?] I try to push it away, but it's difficult because you hear sounds no matter how much you do not want to hear them. You cannot just shut down your hearing. I get very quiet and shut within myself so I can focus better, and I try to close… or to go into myself and just try to do whatever it takes to be in this situation, and yeah, to create a bubble around myself.

Hanna's experience points to the important affective dimension of feeling overwhelmed by others by describing the feeling of anxiety and petrification. Her description of a form of emergency shutdown communicates a feeling of disconnection and detachment from the social situation and other people. Below, Helene, a 17-year-old woman with Asperger's Disorder, expresses a similar sense of disconnection from others in her description of the experience of engaging in eye contact.

> It feels very… Not intimate exactly, but something like it. It's very overwhelming. […] It feels like they can see more. Like, they see me, and I see them, and then I feel insecure about how they see me. Like, how they look back. […] I'm looking at them, and I can see that they are observing me, and that makes me insecure because there is something that I feel like I'm not seeing or something that I do not really know how to, like, see. […] It's like there is a link missing between my perspective and how others experience it. I'm missing a bridge between the two. There is just a gap. […] There is a bridge between me and the other person, and I think they can cross that bridge, but I cannot do it because there is a gap that does not exist for them.

From this excerpt, it is evident that Helene has difficulty finding the words to describe her experience. She feels as though something is missing in her experience of the other person, something that they can see in her but that she cannot access in them. The sense of familiarity with the other is missing, and what features instead is the feeling of insecurity, anxiety, and disconnection from others, described vividly as the experience of a missing bridge. The feeling of being overwhelmed in eye contact is thus simultaneously characterized by the experience of social detachment and alienation. Expanding on another aspect of coming into contact with strangers, Nina describes eye contact as uncomfortable because of the access seemingly enjoyed by the other person:

> It feels weird to sit and look into each other's eyes. Because I feel that people are kind of looking into… If you are sad, then they will see it. Looking into each other's eyes seems a little intimate. […] When you are among other people, and you feel sad or stressed, then you avoid eye contact because you can feel that they can see it on your face instantly. […] I get very uncomfortable and conscious when I have that kind of contact. It's a feeling of shaking, wanting to adjust one's clothing, and feeling that they see me. I become afraid to look wrong or to make a wrong movement.

In this description, the other person seems to come too close and have too much access, which returns Nina's awareness to how she looks through the other person's gaze rather than how they look through hers. Like Helene, Nina experiences a break in the mutuality of social experience manifested through the affective lens of anxiety and discomfort.

The experience of other people as oppressive and unpredictable and of social situations as invasive, chaotic, and claustrophobic run through the various descriptions of social encounters recounted above. Furthermore, this feeling is closely associated with the experience of detachment from and inaccessibility of other people and social meaning. Being sensorially overwhelmed introduces a sense of threat and a desire to move away from rather than toward the world and others. Indeed, a sense of perplexity and petrification seems to have replaced the sense of ease and fluency characterizing social encounters from the perspective of phenomenology. Moreover, these descriptions bear witness to a break in the reciprocity of social experience, which perhaps constitutes the most fundamental feature of phenomenological accounts of social experience (Merleau-Ponty, 1964b; Husserl, 1982).

According to Husserl, the experience of the other person is enabled by a pre-reflective formation of phenomenal unity between the other's body and one's own. This process, termed "pairing," involves what Husserl describes as a "mutual transfer of sense" whereby "this body must forthwith appropriate from mine the sense: animate organism" (Husserl, 1982, p: 113). Pairing thus relies on a sense of familiarity between bodies, a sense of bodies being of the same kind, and is therefore not only a perceptual but also an inherently affective process. The examples presented above speak to this relationship between the presentation of another person in sensory experience and the affective tonality with which that other person appears. Thus, sensory differences in autism destabilize the other person's appearance as a meaningful expressive unity. With Køster's phrasing, we can understand autistic sensory experience as destabilizing the sensorium of the other person by transforming the affective tonality of the social encounter and promoting disengagement and withdrawal. In the following, I will explore various processes and practices of restoring this sense of security in and connection to social situations.

Sensory Urges and Social Deliberations: Strategies of Reconnection

Research participants generally described two ways of dealing with the experience of social interaction. First, in response to the feeling of detachment from one's surroundings, participants described a strategy of seeking out sensory involvement to provide a sense of presence and focus during stressful experiences of a chaotic and threatening sensory environment. This strategy implied an inherent ambiguity, as sensory experience both instituted and resolved the feeling of being overwhelmed in social situations. Second, experiences of others as opaque, alien, and of social detachment were handled by relying on thinking as an approach to social understanding. This strategy provided a feeling of having an access point, a sense of footing, and a point of orientation in an inherently disorienting encounter with another person.

In her description of whirling dancers, Nina communicates how she also experiences the feeling of being overwhelmed by others as an urge to look at them:

> You can see it out of the corner of your eye, and you want to look because it takes up your attention, but you also know that you are sitting and talking with someone. Then there is perhaps someone at another table getting up, and then you want to look at that also.

Being overwhelmed is simultaneously a feeling of being drawn in or disturbed by the surroundings. To relieve this disturbance, Nina describes using headphones with music playing in one ear to shut out what is experienced as intrusive and as an anchor securing her sense of presence in the situation.

> I tend to follow conversations around me, and I cannot shut them out. [If I listen to music, ed.], then my brain does not concentrate on those conversations but on the music. If I start to feel anxious and there are many people, then I can just concentrate on the music […] as a way to get away if anything happens. […] I tend to put some music in my ears because it works as an automatic wall being put up. The bass will thump a little in your ears or vibrate a little. […] Otherwise, I get very restless about not being allowed to look.

The sound and vibration of the music thus function as ways of calming Nina's restlessness and, by experientially separating her from the chaotic surroundings, provide ways to fasten and center her attention on the interaction in which she is engaged. Line, a 17-year-old woman with Asperger's Disorder, describes how a disciplined focus on single aspects of the visual environment can ease this impulse to follow movements or sounds around her. In the following, she describes a dinner party with her parents and their family friends:

> Everything is just turning and turning around you… And I actually have a sort of urge to really know where everything comes from. Every time I sense movement, I look to see what it is, or if I hear a sound, I look to see where it comes from. […] I try to focus on something different. It can be looking out the window or looking down at a… the glass of water in front of me. […] I do not know… Maybe it makes sense somehow, so I can calm down a little by focusing on some object and say, "okay, now it is this thing, which is important."

In this way, Line willfully absorbs herself in a particular aspect of the sensory world to navigate the chaotic sensory environment represented by the dinner party. The glass of water standing in front of her at the dinner table acts as a sensory anchor maintaining her presence in these overwhelming visual and auditory surroundings. She forces the object to appear meaningful and stand out in the muddle and chaos around her by deliberately focusing on the glass. Helene describes a similar strategy in the context of touch:

> I often seek stimuli when I come home to my parents. They know that they should hug me hard. […] I've started to seek out being squeezed or pressed by my parents when I've had a long day. […] I get very overwhelmed in my body and in my head, and then the more hard pressure somehow grounds me. Because everything feels like static electricity, I do not know how to explain it, you know, like if the TV flickers.

Seeking out touch as hard, constant pressure relieves Helene of the static and flickering sense of touch she describes as part of her sensory issues. Like Line's visual absorption in the glass of water, Helene immerses herself in the experience of a clear, demarcated, and steady touch rather than the buzzing or fluttering tactile impressions that she elsewhere refers to as feeling "like bees."

Nina, Line, and Helene describe this deliberate grounding and centering of dispersed attention by seeking out sensory experiences in different ways. While Nina describes an auditory strategy of listening to music, Line describes a visual strategy of focusing on an object in her immediate surroundings, and Helene describes a tactile strategy of seeking firm pressure. In their descriptions, such practice of sensory seeking allows an experiential anchor turning them away from a chaotic and unpredictable situation and toward a sense of presence to the social interaction in focus.

Research participants described another strategy of using reflective attention and deliberate reasoning as an approach to social interaction and understanding the social expressions of others. For example, Nina describes the following situation, where she is asked directions in public transport:

> When someone approaches me like that, I just sit there with cold sweats. I do not know what to answer and fumble with the words. I feel somewhat strange or off and very conscious about my movements. I just feel strange. […] It is as if the world stops. I feel a chill and get all stiff in my body. From feeling quite light and free, I suddenly feel trapped in a cage and have to answer

> […] "Normal people," quote-unquote, would probably just answer her because they are totally used to automatically reading facial expressions, tone of voice, etc. But if I have to answer her, then I first have to figure out what her face is telling me, what her body posture is like, what is her tone of voice, what she is actually saying, what is the mood in the situation. Like, is she looking angry, is she angry, does she seem angry, or is she surprised, happy, etc.? All of these things have to be turned around in my head, and people expect an answer fairly fast, so If you do not answer within, say, 30 s, people will start to question whether you even heard them.

Faced with the stranger's question, Nina describes a feeling of perplexity, insecurity, and motionlessness, almost as if she were a deer caught in the headlights. She describes the prospect of being put on the spot while incapable of answering within the expected timeframe as particularly stressful. Rather than what she describes as an "automatic reading," she goes through a laborious process of thinking through individual aspects of the other's bodily expressions one at a time. In this systematic way, Nina works out what is expected of her in this social situation by drawing on analytic and reflective resources. Like the practice of sensory seeking described above, this strategy applies an active approach to something that would typically be passive or intuitive. Both represent practices of deliberately and actively seeking out social meaning in an overwhelming social situation and thus reconnecting to other people when faced with the experience of their unfamiliarity and unpredictability. In the case of thinking through social interaction processes, it represents a practice of deliberately and laboriously seeking out social meaning through an analytic approach. In the case of sensory seeking, it functions as the deliberate attempt to anchor oneself in single aspects of the sensory surroundings to provide a sense of presence despite the experience of a chaotic and fragmented world.

To understand these strategies better, we can return to Merleau-Ponty's analysis of the relation between object and horizon in perceptual experience. His idea that "it is necessary to suspend the surroundings in order to see the object better" and that "to see the object is to plunge into it" (Merleau-Ponty, 2012, p: 70) helps understand sensory seeking as a way to deliberately plunge into objects. Sensory absorption, whether visual, tactile, or auditory, represents ways of forcing objects to stand out: to tear away figure from ground and thus re-establishre-establish a relationship between foreground and background in experience. In this way, perceptual significance is sought by actively and intentionally singling out particular objects or aspects of the sensory environment. A perceptual grip is thus re-established in a situation that would otherwise appear as a jumbled confusion of fragmented sensory impressions.

As the above analysis has revealed, an essential aspect of coping with the sensory density of social situations is using reflective attention toward something that is typically an intuitive and automatic process. In everyday neurotypical experience, the world appears as a meaningful network of objects and relations whose situationally and contextually relevant aspects effortlessly reveal themselves. In this case, social meaning is wrenched out through an effortful and laborious process robbed of the sense of ease and fluency that phenomenological accounts often ascribe to social understanding and interaction. In the following, I will discuss the implications of this relation between sensory and social experience in autism for discussions on the role of practice, grip, and compensation in disability and psychopathology.

DISCUSSION

The diverse experiences recounted above revealed how social encounters for autistic persons can manifest as sensorially disturbing and chaotic events and how other people appear unfamiliar and threatening in this context. Moreover, in response to the sense of detachment and disengagement from the social world experienced by autistic persons, strategies of reconnection were mobilized that actively sought out perceptual meaning in an inherently strange and unpredictable situation. This analysis highlights both the role of receptivity and responsivity in how other people appear in social experience (Køster, 2021) and the role of practice and activity in the experience of perceptual and social meaning (Salamon, 2012).

Køster emphasizes how the felt sense of the other is a phenomenological structure characterized by reciprocity between what can be termed a style of the perceiver and a style of the perceived.

> Although the expressive style of the other has a definite autonomy and specificity, it cannot be regarded in isolation from the ontogeny and habituated style of perception of the perceiver. In the sensorium of the other these two aspects intertwine intercorporally (Køster, 2021, p: 64).

In this paper, I have explored how habituated perceptual styles in autism destabilize and fragment the sensorium of the other and transform the affective tonality, or felt sense, with which the other appears. The idea that a deep sense of familiarity with others is fundamental to our experience of the social world echoes through this analysis, in this case, by demonstrating how such a sense of familiarity can be disrupted. Concerning the reliance on direct and pre-reflective access to social meaning in phenomenological accounts, this analysis emphasizes how such access is negotiated with the particular form of embodiment enjoyed by the perceiver. In this case, the features of autistic sensory experience introduced an aspect of mediation in social experience, thus pointing to the intuitive givenness of social meaning as a privilege of the able-bodied.

In addition to the importance of perceptual style in social encounters, this analysis emphasizes the importance of practice and activity in the experience of social meaning. In her analysis of maximal grip, Gayle Salamon argues that disabled embodiment reveals a fundamental structure in the relation between self and world, namely that our enmeshment with the world is not characterized by dexterous mastery and expertise (Salamon, 2012, p: 244). Where Hubert Dreyfus characterizes maximal grip as the body's fluent ability to bring the world closer to an optimal gestalt, Salamon emphasizes how embodiment should be understood as something that can be thrown out of balance and vulnerable in the encounter with the world and other people (Salamon, 2012, p: 250). Through reading two disability memoirs, Salamon identifies an aspect of grip what could be termed practice.

> Grip is deployed in both cases not as a way of enmeshing seamlessly with the world, but as a means of methodically composing the body as a substitute for an unthought, and now foreclosed, enmeshment with the world. Grip is the use of deliberate action to order the self as a compensation for lost bodily intentionality (Salamon, 2012, p: 248).

In Salamon's analysis of arthritic embodiment, grip refers to a methodical "taking a grip" on one's body by testing and checking its flexibility, painfulness, and capacity before engaging in a task. This idea of deliberation in the relationship between self and world is helpful in understanding autistic strategies of reconnection as practices of reestablishing a perceptual grip on the social situation. The practice of actively pursuing sensory stimulation in social situations is a way to gain a sense of footing in and grip on the social situation by forcing the world to stand still in order to see it better. These practices thus act as bodily auxiliaries that facilitate a sense of engagement with an otherwise chaotic and unpredictable sensory and social environment, thus emphasizing the possible role of activity in maintaining a sense of intuitive grasp of social meaning.

The role of practice and activity in autistic social experience invites further consideration of how such practices may be supported and facilitated to strengthen autistic persons' experiences of social connectedness. For example, the strategy of seeking out sensory stimulation to maintain a sense of presence in social situations calls for an approach that takes seriously the role of objects and the material environment in facilitating social encounters. As is described both in the historical literature and the current diagnostic guidelines, autism is characterized by abnormalities in the use of objects and the relation to the physical environment (Kanner, 1943; World Health Organization, 2018). Recent debates in psychology and cognitive science concerning the role of objects in social and psychological development have motivated an interest in how the use of objects may facilitate processes of social interaction and communication in autism (Iannaccone et al., 2018; Williams et al., 2018; Manzi et al., 2020). In the field of psychology, a socio-material and ecological perspective highlights the constitutive function of objects and artifacts in psychological and social development, and in the field of cognitive science, enactive, embedded, and material theories of cognition have emphasized the role of interactive context and materiality in social interaction and cognition (Gibson, 1979; de Jaegher and di Paolo, 2007; Malafouris, 2013; Pedersen and Bang, 2016; Rietveld et al., 2018). Thus, an important avenue to pursue further is, on an empirical level, how social aspects of autism relate to aspects typically considered a social, such as a typical use of objects, insistence on sameness, or repetitive behaviors, and, on a theoretical level, how intersubjectivity relates to the material environment [see Boldsen (forthcoming) for further exploration of these issues].

In this article, I have presented descriptions of autistic social experience that emphasize how the surrounding (social and physical) world appears as a strange, overwhelming, and chaotic place. Taking this relational view of social experience seriously implies considering autistic social behaviors as attempts to navigate and meaningfully respond to this uninhabitable world of experience. It is well known that autistic persons employ a range of strategies to function in neurotypical social contexts, such as applying learned rules to social interactions or other ways of masking autistic difficulties (Livingston et al., 2020). Such compensatory strategies are often described as of a cognitive nature and directed toward compensating for theory of mind difficulties in social situations (Livingston et al., 2019). A related point is expressed in the phenomenological literature on autism, where Dan Zahavi and Josef Parnas argue that autistic individuals resort to an intellectually driven approach to social encounters as a way to compensate for "a lack of an immediate, pre-reflective, or implicit understanding of the meaning of social interaction" (Zahavi and Parnas, 2003, p: 67). Here, Zahavi and Parnas build on insights from schizophrenia research, where hyperreflexivity is defined as an overreliance on reflective attention toward oneself and one's surroundings to compensate for a diminishment of the pre-reflective grasp of meaning (Sass and Parnas, 2003; Fuchs, 2010). However, rather than representing such strategies as pathological attempts to compensate for a lack, I think they bear witness to an important sensory and perceptual aspect of compensation, which casts autistic social difficulties and reparatory practices as profoundly world-involving. Furthermore, phenomena such as masking emphasize the disabling and discriminatory effects of social norms and expectations in different societal contexts (Radulski, 2022). An interesting avenue to pursue considering the current study is developing research approaches sensitive to both experiential and societal features of autism that would help address the question of how sensory experience relates and responds to social structures, norms, and expectations in concrete social contexts and interactions.

Autism painfully demonstrates how perception is a continuous project of negotiating the reversibility of gripping and being in the grip of the world, of moving and being moved by the world (Salamon, 2012; Thoma and Fuchs, 2017). This emphasizes how autism can be understood as an exceptional style of being rather than an expression of underlying impairment. Joel Krueger, characterizes autism as "a felt sense of being bodily and affectively out-of-sync with neurotypical spaces not set up to accommodate non-neurotypical styles of being in the world" (Krueger, 2021, p: 3). This mobilization of the notion of style to describe psychopathology draws attention to the qualitative differences between various modes of inhabiting the world rather than a normative understanding of one mode being an impoverished version of another. This understanding of autism ultimately invites phenomenology to interrogate not only typical but also diverging modes of being (see Carel, 2021) and consider how they may productively expand and nuance basic ideas and analyses of how we understand and relate to one another bodily and intersubjectively.

CONCLUSION

In response to an increasing interest in the bodily and experiential aspects of autism from the perspectives of both autism research and phenomenology, this paper has explored the relationship between sensory and social experience in autism. By drawing on qualitative data from an ongoing phenomenological study on social experience in autism, I have argued that sensory differences in autism affect the way social encounters appear in autistic experience on a pre-reflective level. Through an analysis informed by phenomenological accounts of intersubjectivity and perceptual experience, three aspects of how sensory differences affect autistic social experience were identified.

First, the diverse social experiences recounted by research participants revealed how social encounters for autistic persons can manifest as sensorially disturbing and chaotic events. These events appeared with a blurred distinction between the thematized and the tacit in perception, creating an experience of the social situation as experientially invasive and unpredictable.

Second, in this sensorially imminent and approaching world, the embodied expressions of the other appeared alien and with an affective tonality of threat, disrupting the sense of familiarity with others and security in social situations. Thus, sensory differences in autism destabilize the appearance of the other person as a meaningful expressive unity, leaving an experience of opacity and inaccessibility of social meaning that disturbs the possibility of social engagement.

Third, participants described practices of deliberately and actively seeking out social meaning in an overwhelming social situation and, in this way, reconnecting to other people when faced with the experience of their unfamiliarity and unpredictability. One strategy relied on sensory absorption, whereby an experiential distinction between figure and ground was established by actively pursuing perceptual significance. Another strategy applied reflective resources to understand the embodied expressions of others to a sense of footing in a deeply disorienting encounter with another person.

This analysis contributes to emerging phenomenological approaches to autism by pointing to specific ways in which sensory differences are implicated in autistic disturbances in bodily being-with-others and thus stresses the importance of looking at embodied intersubjectivity in terms of its sensory dimensions. By approaching social encounters as sensory and perceptual events, social experience is emphasized as an inherently and irreversibly world-involving phenomenon. This highlights the importance of looking at how contextual and situational elements affect the manifestations of autism and further on the extent to which sensory differences affect autistic experience of the world and others. In addition, the account of sensory and social experience forwarded in this paper pointed to various practices of regaining a sense of perceptual and social grip as forms of bodily auxiliary that mediated a sense of presence and footing in an otherwise chaotic and unpredictable social world. This emphasized the potential role of activity in maintaining a sense of intuitive grasp on social meaning and indicates an important avenue for future research in exploring how such activity may help understand other aspects of autistic social experience and practice.

DATA AVAILABILITY STATEMENT

Due to confidentiality agreements and ethical concerns, supporting data cannot be made openly available. Questions regarding the datasets should be directed to SB (boldsen@ruc.dk).

ETHICS STATEMENT

The study was reviewed by the Danish Committee System on Health Research Ethics. Written informed consent was obtained from the participants and minor participants' legal guardians for the publication of data included in this article.

AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

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EDITED BY
Elizabeth Pienkos,
Clarkson University, United States

REVIEWED BY
Laura Candiotto,
University of Pardubice, Czechia
Tudi Gozé,
Centre Hospitalier Universitaire
de Toulouse, France

*CORRESPONDENCE
Lucy Osler
lucy.osler@hum.ku.dk

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"An illness of isolation, a disease of disconnection": Depression and the erosion of we-experiences

Lucy Osler*

Center for Subjectivity Research, University of Copenhagen, Copenhagen, Denmark

Depression is an affective disorder involving a significant change in an individual's emotional and affective experiences. While the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM) mentions that social impairment may occur in depression, first-person reports of depression consistently name isolation from others as a key feature of depression. I present a phenomenological analysis of how certain interpersonal relations are experienced in depression. In particular, I consider whether depressed individuals are able to enter into "we-experiences" with other people. We-experiences are experiences had with two or more people as a *we* (rather than having an experience as an *I*), experiences that allow one to enter into robustly *shared* experiences with others. I claim that the ability to enter into we-experiences (both actual and habitual) is eroded in depression due to an overwhelming feeling of being different to and misunderstood by others. As such, I suggest that depression should be conceived of as fixing an individual in their first-person singular perspective, thus inhibiting their ability to experience in the first-person plural and to feel a sense of connectedness or togetherness with others as part of a *we*. By attending to on-going impacts of a diminished ability to enter into we-experiences, we can provide a situated and more nuanced account of the changes of interpersonal relations in depression that captures the progressive (rather than static) nature of the disorder. In turn, this analysis furthers our understanding of the emergence, frustration, and erosion of actual and habitual we-experiences.

KEYWORDS

phenomenology, phenomenological psychopathology, depression, sociality, we-experiences, isolation, Ratcliffe

Introduction

Depression is an affective disorder involving a significant change in an individual's emotional and affective experiences. While the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM) lists "depressive mood" as a core feature of depression, it does so "without fully considering what depressive mood is"

(Ratcliffe, 2014, 5). Since the DSM definition of depression references various subjective experiences of depressed patients, it seems essential to ask what these experiences involve in order to understand the disorder. As David Karp puts it: "Research about a feeling disorder that does not get at people's feelings seems, to put it kindly, incomplete" (2017, 67). Phenomenological research into depression has sought to reveal and analyze the experiential structure of the disorder (e.g., Fuchs, 2013a; Ratcliffe, 2014; Stephan et al., 2014; Maiese, 2018; Osler, 2021). Such an approach moves away from characterizing depression as something that someone merely has, to considering depression as something that individuals experience in their lived, situated interactions with the world and others.

First-person reports of depression consistently describe feeling isolated and alone as a key feature of depression. Karp goes as far to describe depression as being, at its core, "an illness of isolation, a disease of disconnection" (2017, 63). In this paper, I explore the feeling of isolation that characterizes many peoples' experiences of depression by analyzing how interpersonal relations in depression are impacted. Specifically, I consider whether depressed individuals are able to enter into "we-experiences" with other people. We-experiences are a form of experience described in the phenomenology of sociality where two or more people experience something together as a *we*, rather than simply experiencing something as an *I* (e.g., Walther, 1923; Carr, 1987; Szanto and Moran, 2015; Zahavi, 2015). Such experiences are typically described as involving a *felt sense of togetherness* or *belonging* with the others involved. I suggest that the ability to enter into we-experiences is eroded in depression due to an overwhelming feeling of being different to and misunderstood by others. As a result, I suggest that depression involves a fixing of an individual in their first-person singular perspective, thus inhibiting their ability to experience in the first-person plural and to feel a sense of togetherness with others as part of a *we*.

In "Depression in the DSM," I give a brief outline of how depression is defined in the DSM. In "Depression: a disease of disconnection," I highlight how depressive experience is often characterized by a profound sense of isolation and connection from other people, drawing both on descriptions of depression found in David Karp's book *Speaking of Sadness* (2017), as well as on the phenomenological research of Matthew Ratcliffe. I note that while there is much agreement that interpersonal relations are negatively impacted in depression, we are left with the question of which interpersonal relations are specifically impaired and how this accounts for the loneliness and disconnection experienced. To help narrow our search, in "What remains," I draw attention to certain forms of being with other people that appear to remain intact in depression. In "We-experiences," I set out what a we-experience is and what the conditions are for such an experience to arise. Using this analysis, I suggest in "Depression and the difficulty of self-alienation" that individuals with depression often report feeling that their experience is significantly different to others, as well as feeling that other people simply cannot understand them, and this inhibits the ability to enter into we-experiences and feel the sense of togetherness that such shared experiences entail. This allows us to point to a specific kind of interpersonal relation that is experienced as absent in depression. In the penultimate section, "The erosion of habitual we-experiences", I argue that not only is the ability to enter in *new* we-experiences disrupted in depression but, over time, more *habitual* feelings of connectedness with others are also eroded. The erosion of both new and habitual we-experiences in depression renders the depressed individual a perennial outsider, able to observe, understand, and even interact with others but not able to richly share experiences and emotions with them, thus driving feelings of isolation and disconnection. I conclude with a discussion in the final section, "Social disconnection, depression, and other disorders", of how my analysis might help us distinguish depression from other disorders, such as schizophrenia, which also involve experiences of social disconnectedness and isolation.

Depression in the diagnostic and statistical manual of mental disorders

It is generally acknowledged that depression is an affective disorder. Descriptions of depression commonly refer to persistent feelings of isolation, loneliness, disconnection, anxiety, despondency, worthlessness, and hopelessness. The DSM states that at least one of the symptoms of depression is either:

i depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, hopeless) or observation made by others; or
ii markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day.

Alongside this, the DSM specifies that an individual must experience at least four of the following additional symptoms:

i significant weight loss or weight gain or decrease or increase in appetite nearly every day;
ii insomnia or hypersomnia;
iii restlessness or lethargy;
iv fatigue or loss of energy;
v feelings of worthlessness or excessive or inappropriate guilt;
vi diminished ability to think or concentrate, or indecisiveness; or

vii recurrent thoughts of death or suicide.

The DSM also mentions that depression can "cause significant distress or impairment in social, occupational, or other important areas of functioning" (American Psychiatric Association, 2013, 163).

Depression, then, is a disorder that is predominantly defined and diagnosed on the basis of subjective experience. Yet, although the DSM makes explicit reference to experiential disruptions in depression, its descriptions of them are only "cursory" (Ratcliffe, 2014, 5). This perfunctory reference to subjective experience in depression is reflected in much medical research. Even though depression is partly defined on the basis of lived experience, medical literature typically focuses on unearthing the biological dysfunction at the root of depression (Svenaeus, 2013; Ratcliffe, 2014). Now, I am not suggesting that depression has no biological basis. However, uncovering the experience of depression in the context of an individual's situated interactions with the world and others often takes a backseat and this inhibits our understanding of what the disorder is and how best we should go about treating it.[1]

Over the last decade, there has been increased interest in how phenomenology can be used to analyze disturbances found in depression, including disturbances of temporality (e.g., Fuchs, 2013a; Ratcliffe, 2014; Maiese, 2018), personal identity (e.g., Svenaeus, 2013), bodily feelings (e.g., Fuchs and Schlimme, 2009; Fuchs, 2013a), and emotional experience (e.g., Slaby, 2014; Stephan et al., 2014). There has also been increased interest in phenomenological psychopathology in how depression involves impairments to one's social experiences (e.g., Fuchs, 2005, Fuchs, 2013a; Ratcliffe, 2014; Ratcliffe and Stephan, 2014; Wehrle, 2019; Osler, 2021). I follow this trend here and present a phenomenological assessment of the erosion of certain interpersonal relations in depression. What my account offers is a specific consideration of how depressed individuals struggle to share experiences with others as a "we" and how this leaves individuals with a distinct loss of togetherness or connectedness with those around them. This, though, is not to suggest that social disconnectedness is the sole feature of depression, nor a suggestion that social disconnectedness of this kind is not a feature of other disorders. As such, my analysis is intended to be paired with other phenomenological descriptions of depressive experience to provide a full picture of what is distinctive about depression compared to other disorders. In this paper, I will not attempt to provide such a picture. However, I will return to the question of how this analysis might aid us in outlining what is distinctive about depression compared to other disorders, in particular schizophrenia, in the final section ("Social disconnection, depression, and other disorders").

Depression: A disease of disconnection

For the purposes of this discussion, I predominantly draw upon David Karp's descriptions of the experience of depression in his book *Speaking of Sadness* (2017). While there are many memoirs dedicated to descriptions of depression, Karp's draws not only from his personal experience but also from in-depth interviews with others who have struggled with depression. It should be emphasized, though, that depression is a complex disorder and the illustrations of depressive experience contained in Karp's book should not be taken as exhaustive. Nevertheless, the descriptions of a sense of isolation, of feeling cut off from the world and other people, that I take as my focus, are reflective of descriptions found elsewhere (e.g., Plath, 1963; Wurtzel, 1994; Styron, 2010; Ratcliffe, 2014).

Depressive experience varies across individuals and has numerous different facets: from feeling isolated to profound lethargy to anxiety. Nevertheless, Karp notes that "the most insistent theme" (2017, 73) is the effect depression has on relations with other people. While interpersonal experience is by no means the only dimension of experience affected by depression, it is a significant and persistent feature of it. The following passages, taken from *Speaking of Sadness*, depict the experience of diminished interpersonal connection in depression:

> During all this I felt deeply alone. Everyone else seemed to be moving through their days peacefully, laughing and having fun. I resented them because they were experiencing such an easy time of it; I felt utterly cut off from them emotionally. I was angry because there was no way they could understand what I was going through. Their very presence seemed to magnify my sense of isolation. (Karp, 2017, 59)

> The irony…is that depressed persons greatly desire connection while they are simultaneously deprived of the ability to realize it. Much of depression's pain arises out of the recognition that what might make one feel better – human connection – seems impossible in the midst of a paralyzing episode of depression. It is rather like dying from thirst while looking at a glass of water just beyond one's reach. (Karp, 2017, 73)

> As with all feelings and emotions, isolation is experienced in different degrees and hues. Some individuals feel obliged

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[1] Having a rich understanding of the lived experiences that people with depression have might also help distinguish between different kinds of depression.

> to withdraw from virtually all arenas of social life. Most people though, unless they become hospitalized, struggle through their daily obligations, sometimes heroically maintain a façade of "normalcy." Others may continue to associate with friends and family while nevertheless feeling disengaged, uncomfortable, marginal, and profoundly alone. (Karp, 2017, 102)

The peculiarly painful mark of depression seems to lie in the desire to "connect" with other people while feeling robbed of the ability to do so. Indeed, Karp labels this the "paradox of depression" (2017, 91). What is more, Karp identifies a vicious feedback loop that often emerges in depression, where the inability to connect with other people causes such discomfort that depressed individuals ultimately withdraw from social life.

The breakdown or fracturing of social relations in depression has been highlighted in numerous phenomenological accounts (Fuchs, 2005, 2013a; Ratcliffe, 2014; Ratcliffe and Stephan, 2014; Wehrle, 2019; Osler, 2021). Perhaps most prominently, Matthew Ratcliffe, in his book *Experiences of Depression* (2014), describes how feelings of isolation, estrangement, distance from the world and other people are common experiences in depression: "The person is cut off from the world and, most importantly, from habitual forms of interaction with other people" (Ratcliffe, 2014, 31). He describes this profound sense of isolation as involving a loss of a "felt sense of connectedness to others" (Ratcliffe, 2014, 208). According to Ratcliffe, this amounts to a profound shift in how one experiences "being with" others and an erosion of "*certain kinds* of interpersonal relation" (Ratcliffe, 2014, 202, my emphasis). This leads us to ask *how* this loss of connectedness is experienced in depression and *what kinds* of interpersonal relations are impacted.

Ratcliffe claims that the loss of felt connectedness can be experienced in depression in two ways:

i where the depressed person retains a sense of what it is to connect with other people but feels that it is impossible to do so; and
ii a more profound alteration where the very sense of what it is to connect with others is lost altogether.

In (i), the possibility of connecting with someone is still anticipated but the ability to fulfill this connection is experienced as positively absent from the world. Interpersonal situations are experienced as *involving something missing* – the absence itself is saliently felt.[2] The alteration in (ii), in contrast, involves a loss of the very sense of what it is to connect with others – the possibility of connecting with others simply does not surface. This is a more extreme change in the structure of interpersonal experience.

Following Ratcliffe, I predominantly focus on the more commonly reported experience of feeling an absence of connection with others in depression (though I will touch upon (ii) at the end of section "The erosion of habitual we-experiences"). Generally speaking, then, a depressed individual:

> . . .still anticipates experiencing the possibility of interpersonal connection when in the presence of certain others, and she "needs" this kind of connection, as her world is impoverished without it. However, whenever she encounters another person, the kind of relatedness she anticipates and/or needs is not experienced as possible. (Ratcliffe, 2014, 220)

Recently, a not dissimilar description has been offered by Tom Roberts and Joel Krueger of loneliness as an emotion of absence, as "an affective state in which certain social goods are regarded as out of reach for the subject of experience" (Roberts and Krueger, 2021, 185). The social disconnectedness that is described by depressed individuals often includes descriptions of an intense feeling of loneliness. Note, though, that Roberts and Krueger (2021) suggest that loneliness can be experienced as a temporary absence of social goods. Depression, though, seems to involve something more prolonged than a fleeting pang of loneliness – a more sustained experience of one's being connected with others and the goods that such interpersonal relationships bring being eroded away. Importantly, one might be lonely without being depressed; either loneliness might be experienced relatively transient or one might experience loneliness as an experience of absent social possibilities without experiencing other markers of depression. Nevertheless, it seems that the kind of social disconnection that I am interested in in depression, may well be described as involving a persistent form of loneliness.

One distinction I am inclined to draw between the account here and that of Roberts and Krueger (2021) is that while I think the experience of being socially disconnected and isolated from others is an affective experience (Osler, 2021), I would hesitate to describe this experience of disconnection as an *emotion* of absence. Emotions are often thought to be relatively short-lived episodic experiences. Whereas the pervasive kind of social disconnectedness that individuals like Karp report, seems to be a more profound shift in how one experiences one's social world and others. Following distinctions made in the phenomenology of emotions, we might be inclined to describe this disconnectedness in terms of an existential feeling or mood.

We are still left, however, with the question of what *kinds* of interpersonal relations are anticipated by the depressed individual that involve this sense of

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[2] For further work on the positive experience of absence, see Roberts (2019) and the classic example from Sartre (2005) of sitting in a café waiting for one's friend to arrive and their absence being explicitly experienced.

"connection" but are experienced as impossible to fulfill. While Ratcliffe states that there is an erosion of certain kinds of interpersonal relations, he does not explicitly explore which kinds of interpersonal possibilities are affected. There are many ways in which we find ourselves "with" other people and, as I argue in the following section, not all of these are eroded in depression. Indeed, for depression to retain its painful character, some of these experiences of being "with" other people must precisely remain intact.

What remains

While depression is often characterized by feelings of isolation, disconnection, and loneliness, one is not thrown into an entirely solipsistic world. Others still feature in experience and depressed individuals do not seem to lose their ability to apprehend or understand others entirely. To help us home in on what kinds of interpersonal relation are disrupted in depression, I start by considering ways in which we find ourselves "with" others that typically remain intact in depressive experience.

Physically being with others

Karp notes that depressed individuals often withdraw from social activities, spending lots of time on their own. However, he also emphasizes that the isolation of depression does not (usually) begin with physical seclusion. Indeed, the initial pain of isolation seems to be rooted in the feeling of isolation while being physically surrounded by other people. Take, for example, these two descriptions of isolation:

> Oh, I was so alone. I played basketball. I was a member of a team. I had a roommate. But I was so alone. I had lots of friends but I was completely isolated. (Karp, 2017, 105)

> Physically, I was not alone. As always Rose was present and listened with unflagging patience to my complaints. But I felt an immense and aching solitude. (Styron, 2010, 26)

Feeling isolated or disconnected does not neatly map onto physically being around other people or not; I can be at home on my own without feeling isolated or I can be in the middle of a busy party and feel completely alone (Roberts and Krueger, 2021; Tietjen and Furtak, 2021). Although the discomfort of feeling isolated while around others may prompt depressed individuals to avoid physically being with other people, the painful disconnection that is spoken of in depression does not appear to be grounded in being physically absent from others.

Being with others in a shared world

Our sense of reality is intimately tied up with our experience of the world as a shared world. Part of what it is for me to experience the world, people, and objects as really there is that they are not just there for me but for other people as well; "I *experience* objects, events, and actions as public, not as private" in terms of only being there for me (Zahavi, 2003, 110). Being with other people is, at least in a weak sense of the phrase, implicated in our perception of objects and our experience of being in an intersubjectively shared world.

We might suppose that we could lose our sense of being in a shared world with others if we no longer experienced the world as available to other people. While not recognized by the APA, James Angelo suggests that astronauts can suffer "solipsism syndrome," a syndrome described as "the state of mind in which a person begins to feel that everything around him or her is a dream and is not part of reality" (Angelo, 2003, 239).[3] In such cases, individuals report experiencing the world as something that is derived from their own minds, rather than a public world that is available to all. Whether or not this is a bone fide syndrome, we can use this example to consider what it might be like to experience the world as only there for you. For in such a syndrome, any others would be experienced as also derived from your own mind, as not really there. It seems possible that such an experience could involve a total breakdown of interpersonal relations as people are no longer experienced as really existing anymore. This seems markedly different to the descriptions of social disconnectedness in depressive experience; while individuals report feeling isolated or cut off from the world and other people, they do not describe the world not being real or people as not really existing. It seems, then, that being part of a shared world in this basic sense, then, is not lost in depression.

Sense of others as subjects

In our day-to-day lives, we do not experience the world littered by objects that we come to identify as other subjects but encounter the world full of other experiencing subjects (Stein, 1989). A loss of interpersonal connection, then, might arise where we to fail to recognize other humans as other subjects of experience. We can find such an experience in Capgras delusion. Those suffering from Capgras delusion experience other people not as other subjects but as "robots with human bodies" (Salviati et al., 2013, 139). Here, the patient no longer experiences being in a shared world with other experiencing subjects.[4] We might

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[3] For related, but subtly different discussions of experiences of 'unreality', also see Broome (2012) discussion of 'Truman belief syndrome' where individuals think they are living in a pretend reality and discussions of derealization, e.g., Varga (2012).

[4] Stanghellini (2004) also offers a description of schizophrenic patients as lacking a sense of others as people.

also point to the lack of responsiveness and recognition of others as other subjects experienced in catatonia (Takaoka and Takata, 2007; Tandon et al., 2013).

While depressed individuals report feeling unable to connect with others, and even that they feel acutely separated from them, this does not amount to an experience of others as being object-like automatons or not there at all. Indeed, not only does the depressed person still experience other people as experiencing subjects but this seems to be an essential part of the experience of feeling estranged from or cut off from other people. If the depressed person no longer experienced people at all, it does not seem to make sense to say that they feel cut off from people as they would be no people to be cut off from. Moreover, depressed individuals often seem sensitive to the kinds of experiences others are having and feel their own situation to be in stark contrast. Think of Karp's description of how he experienced other people as happy, as carefree, as being able to go about their business in an easy manner. The pain of his own unhappy experience was intensified by his awareness of other people's experience. The loss of connectedness, then, does not seem to arise from an inability to either recognize others as experiencing subjects or from a total loss of the ability to apprehend how others are feeling or what they are doing.

We-experiences

The previous section helps show that not all kinds of interpersonal experiences of "being with" other people are diminished in depression. How, then, might we account for the profound sense of disconnection and loss of togetherness reported by depressed individuals? I now want to turn to a specific kind of interpersonal experience that has recently received a lot of attention in the phenomenology of sociality – shared or we-experiences. The term we-experience is used to denote experiences that we have together *with* others, experiences that we *share*. This strikes me as a promising line of inquiry as we-experiences are typically described as involving a felt sense of togetherness with other people, an affective experience of being experientially unified with others (e.g., Walther, 1923; Szanto, 2016; León et al., 2019).

David Carr, in his 1987 paper "Cogitamus ergo sumus," notes that colloquially there are many ways in which we use the word "we." The phrase "we saw the Eiffel Tower" might simply mean that I have seen the Eiffel Tower on one occasion and that you have also seen the Eiffel Tower on another occasion. In this instance, we have both seen the Eiffel Tower but our sightings took place at different times. Carr suggests that here one could quite happily replace the "we" in this expression with "you and I." However, Carr argues that this substitution is not appropriate if the phrase "we saw the Eiffel Tower" is meant to capture that we saw the Eiffel Tower *together*. In this second case, there is something lost in the substitution. What Carr is highlighting is that there is a phenomenological difference in experiencing something on one's own compared to experiencing something together with someone else. When referring to experiences we had together, the word "we" is not just shorthand for "you and I" but designates a particular *kind* of experience that we had with someone else, where the experience of seeing the Eiffel Tower was not just *my* experience but *our* experience.

The term "we-experience" designates a special kind of experience that is "no longer simply experienced by me as *mine*, but as *ours*" (Zahavi, 2015, 90). Discussions of robustly shared we-experiences have their roots in classical phenomenological work, such as Edmund Husserl, Max Scheler, and Gerda Walther. Here, I will focus on the more contemporary work of Dan Zahavi, who has written extensively on this topic. My reason for doing so is primarily practical, as Zahavi has devoted considerable time and pages to clarifying what early phenomenologists meant by this term and spelling out the requisite conditions for a we-experience to emerge. Zahavi (2015, 2019) argues that experiencing something with another together as a "we" involves: (i) reciprocal other awareness and (ii) integration (also see León et al., 2019). Let us look at these two conditions in turn.

Reciprocal other awareness

In order for a we-experience to arise, the first thing we need is at least one other person.[5] If we are to see the Eiffel Tower *together*, I must be aware that you are there. Importantly, though, it is not enough for me to simply be aware that you are also present. I could be standing behind you and aware that we are both looking at the Eiffel Tower but this would not be sufficient to characterize our experience as looking at the Eiffel Tower *together* as you have no idea that I am there at all. You must *also* be aware of me looking at the Eiffel Tower. Crucially, though, what we need is not just parallel awareness of one another – for I might be aware that you are there, you might be aware that I am there, but neither of us are aware that we are attending to one another (e.g., if we keep glancing at each other but without noticing the other's glances). What is required is a *reciprocal* awareness, where both you and I are mutually aware of being attended to by the other (Zahavi, 2015, 2019).

While reciprocal other awareness is required for a we-experience to arise, it is not sufficient. For instance, I could be eating lunch in a café at the same time as you and we

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[5] For simplicity, I will focus on we-experiences that arise between two people. I take it, though, that we can have we-experiences with more than one other person.

might be reciprocally aware of each other. However, at this stage it is not appropriate to say that we are eating lunch together. What Zahavi claims is missing here is the *integration* of our experiences in an appropriate way that transforms our experience from the first-person singular to the first-person plural (Zahavi, 2015).

Integration

While the notion of reciprocal other awareness is relatively simple, what does it mean for our experiences to become integrated? Broadly speaking, the word integration is used to capture how two people's experiences come together in a way that transforms the experience from one that is had as an "I" to an experience that is had together as a "we." The starting point for this integration of experiences is that it must make a difference that we are experiencing something together rather than alone. Zahavi describes this in terms of the individuals involved feeling that the "structure and quality" (2015, 90) of their experience is impacted by the other's experience. When two strangers are looking at the Eiffel Tower, they might have reciprocal awareness of one another but just happen to be gazing at the Eiffel Tower at the same time. This would be a case of coinciding or parallel experiences. Contrast this with two friends who have come to gaze upon the structure. In looking at the Eiffel Tower, they direct one another to different aspects of the tower, enriching each other's appreciation of it, enjoying the experience more because it is something that they are discovering together rather than apart. In this second case, part of what it is for the friends' experiences to become integrated with one another is that their experience of seeing the Eiffel Tower is intertwined with and interdependent on one another's experience. In other words, it *matters* that the other person is involved.

However, intertwinement and interdependence of experience will not suffice. If I trip over outside and someone laughs at me, my embarrassment is intensified by the other's mirth. We could not have had this experience apart – my embarrassment is bound up with their seeing me and their delight is bound up with watching me fall. Yet, this does not amount to a we-experience. The integration we are looking for is *a special kind of integration*, one that involves what Gerda Walther (1923) calls an "inner bond" or "feeling of togetherness."

What, then, does this special kind of integration involve? Note that this integration is not meant as some kind of fusion of experience into some group mind or group consciousness – the participants are not coming together as *one undifferentiated subject*. Zahavi emphasizes that "[a] we, a first-person *plural*, is not an enlarged I" (Zahavi, 2019, 5). Experiencing something together as a *we* involves a particular kind of relation *between* the participants and a "relation between" implies a plurality of participants. Nevertheless, "the difference between self and other cannot remain *too salient*, since this will prevent the required unity and integration from actually happening" (Zahavi, 2019, 5, my emphasis). For a we-experience to occur, each participant's experience is transformed in a way that emphasizes their similarities while downplaying the differences (Zahavi, 2015, 2019; León et al., 2019), so they each come to experience themselves as "one of us" who is having the experience.

Zahavi suggests that you cannot enter into a we-experience if you are rooted in your first-person singular perspective; what is characteristic of the first-person singular perspective is that one's experience is given exclusively as *mine*, whereas in a we-experience, the experience is given to the participants as *ours*. This transformation occurs through "self-alienation." Self-alienation has rather negative connotations, however, it is used here to capture a process that involves appreciating and adopting another's perspective on oneself (Zahavi, 2019, 6). As I understand it, the alienation that occurs is a *distancing* from your own I-perspective through an incorporation of another's perspective on you. This is rather a tricky concept to articulate, however, I suggest it is one that we are all familiar with.

Let me illustrate this with an example: I am sitting doing a jigsaw puzzle. I am struggling to find the right pieces, have a pain in my back from sitting at the table for a long time, and am starting to lose interest in the whole thing. My experience is suffused by a variety of experiences *from my perspective*. Then you come along and start putting in pieces of the puzzle too. I understand that your perspective on me is "you are doing a jigsaw puzzle" and I have the same perspective on you. Under your gaze, I appreciate your perspective of me and I can adopt and identify with your perspective on me as doing a jigsaw puzzle in a way which downplays the frustration and discomfort that I experienced before you came in.

What Zahavi claims is that through self-alienation I not only achieve some distance from my I-perspective but can also come to *feel myself as like you*. If I experience myself through your eyes as "doing the puzzle" and experience you as "doing the puzzle," I can come to experience myself as *one of us* doing the puzzle. By experiencing myself through your eyes, my own I-perspective is "downplayed." Rather than experiencing the situation as "I am doing this" and "You are doing that," the *I* recedes into the background in favor of a sense of mutual, shared experience; those elements of the experience that only feature for me (for instance my back pain or frustration) are less prominent than the elements that we are experiencing together (the doing of the jigsaw puzzle). In this way, the similarities between myself and the other are accentuated and the differences minimized, giving rise to an experience of doing the puzzle *together* as a "we." Importantly for our purposes, a characteristic feature of experiencing something as a "we" is that we not only have a similar experience to another person, we *feel* a sense of togetherness or connectedness with them.

At first glance, the transformation from an I-perspective into a we-perspective looks rather laborious. Zahavi requires us to first appreciate the other's perspective on oneself, identify with it, and incorporate it into how one sees oneself thus distancing oneself from one's I-perspective and shifting to a we-perspective. However, he argues that this transformation typically does not occur through onerous cognitive reflection but arises pre-reflectively.

Failures of integration

We can enrich our understanding of how we-experiences arise and the notion of self-alienation by considering how the requisite integration might fail to come about. Returning to our puzzle example, imagine that my back pain happens to be very severe. This pain is only experienced by me, it is not something common between the two of us.[6] Where this difference in my experience and your experience is so prominent, it seems unlikely that the similarities between us will be accentuated enough for us to come together in a shared first-person plural perspective; my own exclusive experience is too pronounced to fade into the background in the requisite manner. I think it likely that this kind of pain might jeopardize self-alienation from the I-perspective and hinder identification with the other as a "we." This illustrates how one might remain "rooted" in one's first-person singular perspective.[7]

I also think that my adoption of your perspective on me will only take place if I take you to understand me with a degree of *accuracy*. Say I am sitting at the table sorting through jigsaw pieces looking for particular shades of green I like because I want to repaint my apartment. You come along and I am aware that you think I am just sorting the jigsaw pieces into colors in order to complete the jigsaw. If your perspective on me is that I am "doing the puzzle" when I am actually examining the pieces because I like the color of them, I am not likely to adopt your perspective on me. It seems difficult to see how we could come to share an experience of doing the puzzle together if I think you have mistaken what I am doing or experiencing; there seems to be little ground here for anything to be shared. Indeed, that you seem to have misapprehended what I am doing can make me feel a sharp contrast between myself and you. As such, I take it as necessary that I must feel *understood* by you if I am to adopt this self-alienating perspective on myself and come to identify as "one of us."

Depression and the difficulty of self-alienation

Having outlined the conditions for the emergence of a we-experience, let's explore how entering into a we-experience might be inhibited in depression. As detailed above, entering into a we-experience with others involves (i) reciprocal other awareness and (2) an integration of the participants' experiences into a "we." As noted above, depressed individuals do still experience others as experiencing subjects in the world. It does not seem to be the case, then, that depressed individuals are incapable of having reciprocal other awareness with others. Being depressed does not stop me being aware of your presence and aware that you are also aware of me.

What about the second condition: integration? As discussed above, part of what is required for one's own experience to become integrated with another to form a "we" is the feeling that one's own experience is intertwined with and independent on the other's experience, that the participants are mutually affecting one another. Some claim that in depression, individuals no longer feel themselves affectively moved by the emotions or bodily actions of actions, resulting in a loss of "interaffectivity" between subjects (e.g., Fuchs, 2005; Varga and Krueger, 2013). Think, though, of the descriptions that Karp gives of the pain of being in the presence of others when depressed, how seeing others smoothly engage with the world makes one's feeling of isolation even more acute. In a broad sense, then, depressed individuals do still seem to be affected by others' experiences, even if it is in terms of feeling more profoundly disconnected and distant from them.

However, a special integration is required for a we-experience. As Zahavi puts it, for two (or more) people to become integrated into a "sense of us," individuals need to be able to downplay their experiential differences in favor of their similarities. I suggest that in depression the difference between oneself and others is experienced as *too salient* for the requisite integration to take place. In the following, I explore two features of depressive experience that might disrupt the kind of self-alienation required for we-experiences: (i) the prominence of one's own exclusive "I" experiences and (ii) a profound feeling of being misunderstood by others.

The prominence of "I" experiences

As discussed in the jigsaw puzzle example, if experiences that are *exclusively mine* are too prominent, this might hinder

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[6] Note that this is not to suggest that pain can never be shared. While some have argued that sensations cannot be shared, I will remain neutral on this here. It also is not the case that only negative experiences might prevent the emergence of a we-experience. I could be so ecstatically happy about an upcoming date that this happiness also is experienced as something that is not common between us and work to hinder the experience of doing the puzzle together as a we.

[7] While I have focused on how a salient affective experience that only one participant might frustrate the emergence of a we-experience, structural differences might also have this impact. For instance, if there is a distinct power imbalance between myself and the person doing the jigsaw, this might hinder my ability to feel myself to be enough 'like them' for a we-experience to arise. Thank you to Laura Candiotto for raising this example!

the ability to distance oneself from one's first-person singular perspective. I used severe back pain as an example of an experience that is *mine* (and not yours) which might be experienced as too persistent and prominent to downplay in favor of the experience that *we* are doing a jigsaw *together*. Even when performing something that from the outside might look like a we-experience, I might be focused upon my back pain and thus "fixed" in my I-perspective. When this occurs, the similarity between our experiences that arises in the context of doing a common activity is not sufficiently strong to outweigh the felt difference between what *I* am experiencing and what *you* are experiencing.

Many felt dimensions of depressive experience might give rise to prominent and persistent experiences that make it hard to feel the similarity between oneself and others. For instance, feelings of tiredness, lethargy, anxiety might all be experiences that are hard to distance oneself from. These prevalent, and importantly unshared, experiences of *mine* might prove too difficult to downplay. Even where one is involved in some kind of collective activity, one's I-perspective might continue to be *too salient* for the integration and transformation of one's experience of doing or feeling something together as a "we." This, I think, nicely captures Karp's descriptions of how a depressed individual might continue playing basketball with friends as part of a team, an activity that looks like it might provide fruitful ground for the emergence of a we-experience, while no longer feeling a sense of togetherness with the other players. The felt absence that is experienced is the missing feeling of togetherness or connectedness that arises when we do or feel things with others as a "we." This absence might be felt particularly strongly when individuals are taking part in a common activity, an occasion where one might expect a sense of togetherness to manifest, and yet this connectedness fails to come about, leaving the depressed individual with a distinct sense that something is off, that something anticipated is missing. This feeling of absence can, in turn, fuel feelings of frustration, anger, even resentment at the ease with which others seem to connect with one another. This piles on more affective experiences that mark the depressed person as different to others, experiences that further fix them in their own I-perspective. Thus, we can see how a vicious cycle can emerge as one reacts with disappointment and anger to one's experienced lack of connectedness. This captures the very paradox of depression that Karp describes – the real desire and even need to connect with others, while feeling oneself incapable of achieving this connection.

In a similar vein, there are a number of studies that suggest that depressed individuals are prone to ruminate on their experiences (e.g., Takano and Tanno, 2009; Krieger et al., 2013). Rumination involves repetitive and reoccurring thoughts focused on one's own experiences (and symptoms). As Krieger et al. (2013, 502) note, "brooding (referring to self-critical moody pondering) has been shown to be associated with higher levels of depression." Such rumination seems to further embed someone in their first-person singular perspective, making it hard to appreciate and adopt the other's perspective oneself and to distance oneself from the "I" in a way that allows for a shared experience with another as a "we" to arise. Rumination also seems to debar self-alienation. Moreover, it seems plausible that if a depressed individual feels a lack of connection with others, they might critically brood upon this change in their interpersonal experiences. This might lead to a viscous circle where depressed individuals increasingly reflect on their sense of isolation while around other people, thus accentuating feelings of being different from others and inhibiting their ability to feel togetherness with others as part of a "we."

Feeling misunderstood

Feeling profoundly misunderstood by others is another common symptom of depression. As one of the reports from Karp (2017, 59) puts it: "I felt utterly cut off from [other people] emotionally. I was angry because there was no way they could understand what I was going through". This feeling of being misunderstood does not simply refer to instances where someone mistakes or misinterprets what a depressed individual is doing or experiencing. Rather, it is a profound sense that *no-one* is able to understand their depressed experience, that others *cannot* understand their experience of the world as drained of connection, significance, hope or energy. The feeling of not being understood that marks depression is often experienced as inevitable and irreversible.

As mentioned above, feeling misunderstood stymies we-experiences. If a depressed individual takes their own experience to be unlike the experiences of others, there seems little ground for experiencing oneself as "like others." Moreover, if a depressed individual does not think that other people can ever understand them, they are unlikely to adopt and incorporate other peoples' perspectives of them. This deep sense of feeling of being misunderstood, then, seems to prevent the kind of identification with others that is involved in a we-experience. Again, the depressed individual experiences themselves as *too different* to others for a we-experience to emerge, leaving the depressed individual feeling like an outsider, cut off from the rich feeling of sharing experiences and emotions with others.

The erosion of habitual we-experiences

Even if persuaded by the argument that the ability to enter into we-experiences is inhibited in depression, some might wonder how helpful this is for more broadly understanding interpersonal experience in depression. As Zahavi (2019) himself remarks, we-experiences are not ubiquitous experiences.

Indeed, some even suggest that we-experiences might be quite peculiar or even rare occurrences (Szanto, 2018) (though I am inclined to think that this is not the case). It might seem to some that my analysis only points to a small subspecies of interpersonal relation that is eroded in depression. How, then, can this help account for the profound and pervasive sense of disconnection from others that depression involves? In this section, I explore how difficulties with self-alienation and identification might not only prevent depressed individuals from experiencing new we-experiences with others but might have a detrimental effect on more habitual feelings of togetherness. Understanding this more habitual sense of togetherness captures how our intersubjective worlds often are experienced as marked with a connectedness with others, if when we are not engaged in an explicit we-experience, even when we are alone.

Habitual we-experiences

Gerda Walter notes that the feeling of togetherness experienced in what she calls "actual we-experiences" can often "dissolve quickly" (1923, 48). However, she does not conclude from this that we-experiences only ever give rise to transitory feelings of connectedness and belonging. Rather, she suggests that in certain relationships, the feeling of togetherness of a we-experience does not simply disappear but, over time, can be *sedimented*. When this occurs, we come to experience a background, habitual sense of togetherness with those individuals without the need for a full we-experience to occur.

Take our friends who were looking at the Eiffel Tower together. Imagine these friends continue to travel together, exploring the sights of France and beyond. Over time, their experience of being "one of us" becomes second nature:

Just as certain intense and lively emotions (e.g., love) can sediment themselves and transform into more habitual states of mind, so can a similar sedimentation take place in the case of unification. To see this, think of the difference between the feelings of unification or togetherness characterizing a friendship – fervent, lively and constantly reinforced at the beginning, they eventually become sedimented background-feelings. Unification, in this case, is first explicit, but becomes habitual over time. (Zahavi and Salice, 2017, 520)

With some people we do not need to continually "rediscover" our sense of togetherness with them through the performance of a we-experience. That sense of togetherness becomes a background feeling that pervades our relationship.[8] According to Walther, this background sense of togetherness is more common than actual we-experiences (1923, 46).[9]

The idea that we experience a habitual sense of *we*-ness in some of our interpersonal relations becomes more apparent if we consider what it is like if this habit is disrupted:

> We know that a habit of togetherness forms because once it is ruptured, either by conflict or death, one experiences a profound loss or undeniable change. . .The death of a lover, for example, results in an acute awareness of how one is used to existing in and relating to the world. (Calcagno, 2012, 100).

With the loss of a lover, the background sense of connectedness with them that we are used to feeling is revealed through its absence. We can also think of less extreme examples where this occurs, for instance, when we drift away from certain friends, or in cases when someone is excluded from a friendship group. When we take into account these habitualized experiences of togetherness with other people, we capture a deeper, more implicit, sense of belonging that we often experience with friends and family – a "sense of us" that is more pervasive, and less demanding, than the more explicit we-experiences described above.

The erosion of habitual togetherness in depression

Why is this discussion of habitual togetherness relevant to us? I think it points to a broader sense of connectedness that is also vulnerable to corrosion in depression. While the identification with another as a "we" might become second-nature with certain people, it is not immune to conflict. While Walther does not expound upon this, habits are neither determinate nor fixed. While I might have a habit of running down my stairs every morning, if I sprain my ankle, I am not able to act upon this habit. If my ankle is painful for a long period of time, my habit of running down the stairs may even disappear and even after my sprain has recovered I may continue to walk down the stairs rather than run down them. This habit may also be disrupted if my environment changes and I move to a ground-floor flat.

To be sustained, habits need to be enacted, otherwise they might change, disappear, or become disrupted (Maiese, 2016; Candiotto and Dreon, 2021). A habitual feeling of togetherness, an example of what Candiotto and Dreon (2021) describe as

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[8] One might be concerned about the implication of a sedimented background-feeling of togetherness. It risks sounding like an unconscious emotion, a feeling that we are not aware of. Indeed, Szanto (2018) expresses this very worry. However, I agree with Szanto when he states that it would be a mistake to characterise this as a feeling that we are not aware of. Rather, the habitual feeling of *we*-ness is felt but it does not need to go through an explicit performance of an actual we-experience; it is not that we are not aware of thinking of ourselves as a *we* but that we come to do so in an enduring and background way.

[9] For a more in-depth discussion of Walther and habitual we-experiences see: Zahavi and Salice, 2017; Osler, 2020; Wilde, 2021.

a "habit of feeling," can also be dislodged. Think of how our traveling couple might get into an argument one day. Their habitual identification with one another as a "we" might be replaced by a feeling of being at odds with the other. Their background feeling of togetherness is not, then, impervious; it can come into conflict with other experiences. It might be that the couple's habitual sense of *we*-ness is quite robust and perhaps the argument ruptures their sense of togetherness in that moment but their deeper sense of being "one of us" is not permanently eroded. As Lohmar (2014, 52) remarks, habits can be "sluggish" to change. Nevertheless, if arguing becomes common between them, a "crisis of habit" (Candiotto and Dreon, 2021) might occur where there is a conflict between the tense situation between the pair and the hitherto experienced habitual sense of togetherness. If this crisis continues, the sedimented sense of togetherness might eventually evaporate and instead be replaced by a sense of disconnection from each another.[10]

Just as Zahavi anticipates that where differences are felt too saliently this will jeopardize a felt sense of togetherness in an actual we-experience, I suggest that differences felt too saliently will, over time, also disrupt the feeling of togetherness in habitual we-experiences. If someone consistently experiences their own I-experiences as hyper-salient, unique to themselves, and even not understandable by others, this can work to unseat these more implicit feelings of togetherness. Where someone with depression feels that their experience of the world is so alien to their friends, partner, or family, seeing the other no longer awakens the habitual sense of connectedness, they feel their own experience as in contrast to the other, as inaccessible and not shareable between them. Just like how an argument can temporarily come into conflict with our usual sense of togetherness with a loved one, this might not immediately dissolve that sense of togetherness. However, if this feeling of being different to the other continues and the habitual sense of togetherness is no longer sustained or revitalized, it will weaken and erode. We might also suppose that as depressed individuals feel increasingly disconnected from those around them, they get caught in a viscous feedback loop, where they feel increasingly like their experiences are markedly different to other people and that there is no chance that others will understand what their experiences are like.

The loss of these background feelings of togetherness are likely to feel especially painful as they often involve a disruption of personal, long-term interpersonal relations. Not only is there a felt absence of a usually present togetherness, the absence itself is experienced as something unfamiliar. This might help us make sense of Ratcliffe's claim that depressed individuals *expect* there to be a sense of connection with others but experience it as impossible to fulfill. It is not just that we go around expecting to strike up new we-experiences with everyone we meet but that many of our day-to-day interpersonal relationships are *usually* characterized by a sense of connectedness resulting from the sedimentation of actual we-experiences. When our habitual feelings of togetherness are disrupted, it can change how we find ourselves in the world, rendering it strange and unfamiliar.

By accounting for how habitual experiences of we-ness, or togetherness, are eroded in depression, I think we get closer to understanding how being rooted in the first-person perspective might give rise to a profound sense of disconnected from other people. If a felt sense of being different to and misunderstood by others comes into conflict with sedimented feelings of togetherness, we can appreciate that it is not only *new* interpersonal relations that are affected but also our *already established* interpersonal relationships.

Interestingly, the framework of habit also allows us to account for how different interpersonal relations are differently affected in depression. The time I spend with my partner as a couple, as well as the quality of our connection and companionship, is likely to sediment a deeper sense of togetherness between us than I experience with my work colleague. Thus, we might predict that in an episode of depression it will take longer for the sense of togetherness with my partner to completely erode than in the case of my work colleague. We might also predict that the disruption of my sense of being *one of us* with my partner will be more unfamiliar, more strange, more painful. This, then, helps capture how interpersonal relations breakdown at different rates and intensities in depression.

Adding habitual feelings of togetherness into the picture helps capture the "downward spiral" of depression (Karp, 2017, 91). A person does not usually wake up one day in the throes of major depression. Rather, depression is something that progresses, that, unless treated, gets worse. The idea that there are gradations of sedimented we-experiences might account for how the feeling of connectedness to others slowly seeps out of the world (rather than evaporating all at once). Moreover, it introduces the idea that over time, as habitual feelings of we-ness erode and new we-experiences fail to arise, we may come to experience a habitual sense of *dis*connection.

Where a habitual we-experience is unsettled by an inability to distance oneself from one's first-person singular perspective, this does not necessarily immediately erode that habit. So, when we see that person again, we might still expect to feel a sense of connection with them that is then (painfully) disappointed. This fits Ratcliffe's description of the depressed person who retains a sense of what it is to connect with other people but feels that it is impossible to do so. However, over time, as the habit of feeling a sense of togetherness with others is eroded it might be replaced with a new habitual sense of *dis*connection. This formation of a new habit of disconnection might help us understand how a depressed individual transitions from

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[10] This might also occur in a less dramatic way. Our habit of feeling and thinking as a *we* could simply fade away if the habit does not come to fruition frequently. This might happen when a couple 'drifts apart'.

retaining a sense of what it is to connect with others to the more profound alteration where the very sense of what it is to connect with others is lost.

In the later stages of major depression, the sense of disconnection becomes the new "normal" and not only does the ability to enter in we-experience disappear, but the very possibility of such relationships evaporates, leaving the depressed individual further cut adrift from other people. What might start off as occasional episodes of failing to connect with others can sediment into a more pervasive sense of the acute absence of connection and finally cement into a hopeless sense of disconnection. As depression progresses, the very sense of what is possible alters. Revisiting what I said above, one way to conceive of this progression is to think of depression as involving an alteration in mood or existential feeling, a very shift in the way the world affectively unfolds around us and presents us with the possible (Ratcliffe, 2014). When depression is at its most serious, the very intersubjective world upon which the possibility of we-experience rests, can itself be eroded leading to a deeper and more profound rupture of intersubjectivity. Taking both actual and habitual we-experiences into account, therefore, not only helps us understand what kinds of interpersonal relations might be disrupted in depression that results in isolation, but also helps us construct a picture about how depression progresses. This, I think, not only enriches our understanding of social impairment in depression but also reflects depression's progressive, rather than a static, character.

Social disconnection, depression, and other disorders

As the reviewers of this paper both pointed out, social disconnection and impaired intersubjectivity are also reported in disorders other than depression, such as autism (Krueger and Maiese, 2018; Boldsen, in press), schizophrenia (Fuchs, 2005; Sass and Pienkos, 2013; Van Duppen, 2017; Salice and Henriksen, 2021), and (delusional) melancholia (Fuchs, 2005). In acknowledging this, though, we do not want the boundaries between these disorders to collapse. How, then, might we recognize that disrupted intersubjectivity is a feature of more than one disorder, without losing the experiential differences between them? My answer to this is threefold:

i while allowing that impaired ability to enter into and sustain we-experiences might occur in other disorders, what impairs this ability might be different;
ii different forms of interpersonal relationship might be impacted in different disorders, which impacts how social disconnectedness and disrupted intersubjectivity are experienced; and
iii there may be other characteristic features of a disorder, such as temporal experiences, bodily experiences, experiences of agency and autonomy, that differentiate it from depression despite involving a similar experience of social disconnectedness. To illustrate these points, I will consider how depression differs from schizophrenia (though I take it that this tripartite framework is applicable to other disorders as well).

First, there are reasons to suppose that schizophrenic individuals might also struggle to enter into we-experiences with others (Van Duppen, 2017; Salice and Henriksen, 2021) and, thus, my analysis of how we-experiences can be disrupted might also be helpful for exploring social disconnection in schizophrenia as well as depression. However, it is interesting to note that we-experiences can fail to arise for reasons other than those I have detailed above (i.e., the prominence of "I" experiences, rumination, and feelings of being misunderstood). According to practitioners such as Minkowski (1970) and Fuchs (2013b), schizophrenic individuals often experience temporal fragmentation that results in "reduced attention spans, disturbances in planning, initiation, sequencing and synchronization of speech as well as in the performance of other activities" (Fuchs, 2013b, 88). This temporal fragmentation can also give rise to what Fuchs describes as damaged basic self-coherence which disrupts the flow of temporal experience and threatens a sense of continuous selfhood and mental life. Fuchs suggests that a consequence of this is that schizophrenic patients experience "difficulties in recognizing faces and in interpreting facial expressions or gestures" (2013b, 92). This temporal rupturing seems likely to hinder the emergence of we-experiences in various ways, including inhibiting the individual's ability to empathetically perceive what the other is doing and experiencing (an essential component for we-experiences as detailed above), as well as inhibiting the ease with which an individual might engage in shared activities and joint attention – activities that are fertile grounds for the emergence of a "we." Importantly for our purposes, while an inability to enter into we-experiences might be a feature of schizophrenic experience that is shared with depression, what gives rise to the disruption appears to have certain differences to the case of depression. This, then, might account for both an overlap between the disorders, while maintaining their distinctive experiential features.

Second, there might be other intersubjective relations hindered in schizophrenia that remain intact in depression. As mentioned above, there is evidence that schizophrenic individuals often struggle to understand the expressions and gestures of others. This diminished ability to understand others is likely to give rise to social disconnectedness, leaving the schizophrenic individual in a world of uncertainty about others' experiential lives. This, then, might be an additional dimension of intersubjective disruption in schizophrenia that contributes to a broader sense of isolation but one that is not shared with depression. Adopting a fine-grained analysis of exactly *how* social relations are affected in various disorders will help us map out differences, as well as similarities, between such disorders.

Third, while I have argued that social disconnectedness is a common (and often central) feature of depressive experience, this is not to suggest that this is the only feature of depression. Distinctions between depressive experience and schizophrenic experience, then, can also be found by attending to additional features of these disorders – such as temporal experience, bodily experience, agency and autonomy, and other affective experiences. For example, the occurrence of thought insertion and disturbed for-me-ness (as detailed by Henriksen et al. (2019)), are considered by many to be characteristic features of schizophrenia but not of depression. As such, we can also account for experiential differences between disorders by looking beyond social dimensions to other distinctive features.

It should also be noted that experiences of social disconnectedness can flow from a disorder due to stigmatization. In certain instances, we might not want to suggest that feelings of isolation, disconnection, and loneliness are necessarily a core characteristic of a disorder while also recognizing how the stigmatization of various "mental health" disorders can leave individuals at risk of social exclusion and social stereotyping (Osler and Krueger, 2021).

All of this is to say that experiences of social disconnectedness, isolation, and eroded or disrupted intersubjective relations can come in many flavors and the experiential dimension of disorders are typically complex and textured. As such, I think that my analysis of the erosion of we-experiences may help us identify similar disruptions in other disorders, without the risk of losing our ability to reveal what is distinctive about depressive experience.

Conclusion

Phenomenological psychopathology has urged us to consider the breakdown of social relations as not simply a result of depression but a core feature of what it is to experience depression. I have sought to enrich this view by not only drawing attention to the isolation and disconnection that is experienced by many depressed people but considering which kinds of social relationship might be impaired in depression. The characteristic feature of we-experiences is that we identify with others as "one of us" and experience various actions and emotions as "ours." This gives rise to a felt sense of togetherness or connectedness with others as a "we," of not only sharing a world in a broad sense but of sharing experiences together. Importantly, this feeling of togetherness can arise through the performance of new we-experiences but also where that togetherness becomes a habitual feature of certain relationships. I have suggested that in depression the feeling of being different to and misunderstood by others fixes a person in their first-person singular perspective, thus shutting off their ability to experience things as part of a "we." Experiencing something as a "we" precisely involves experiencing something that could not be had apart and what is threatened is not only a sense of connectedness with others but an openness to being influenced and entangled with the experiences of others, of having the world unfold to us in new and exciting ways.

Exploring exactly what kinds of social relations might be compromised in depression clearly gives us richer insight into the nature of the disorder, deepening our understanding of the pain and loneliness that depressed individuals often suffer. In turn, this analysis furthers our understanding of the emergence, frustration, and erosion of actual and habitual we-experiences. Adopting this situated approach to depression, though, also helps us to understand how depression might worsen over time, as experiences of disconnection become the norm and one's very hope of sharing experiences with others seeps away. Situating depression, then, is not only a case of situating depression in the lived experience of depressed individual, but of situating the disorder across *time* as something that dynamically progresses. While phenomenology has a long history of situating and understanding psychopathological disorders in the context of a person's experience, world, and interactions, more attention needs to be given to the dynamic temporal profile of psychopathological disorders.

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.

Author contributions

The author confirms being the sole contributor of this work and has approved it for publication.

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Conflict of interest

The author declares 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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A phenomenological exploration of self-identified origins and experiences of body dysmorphic disorder

Shioma-Lei Craythorne*, Rachel L. Shaw and Michael Larkin

Institute of Health and Neurodevelopment, Aston University, Birmingham, United Kingdom

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EDITED BY
Elizabeth Pienkos,
Clarkson University,
United States

REVIEWED BY
Fiona Holland,
University of Derby,
United Kingdom
Rosa Ritunnano,
University of Birmingham,
United Kingdom

*CORRESPONDENCE
Shioma-Lei Craythorne
s.craythorne2@aston.ac.uk

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Body dysmorphic disorder (BDD) is a debilitating mental health condition that presently affects ~2% of the general population. Individuals with BDD experience distressing preoccupations regarding one or more perceived defects in their physical appearance. These preoccupations and perceived distortions can have a profound impact on key areas of social functioning and psychological health. Individuals' BDD origins have not been explored in significant depth and have been, often unhelpfully, conflated with social media usage and exposure to idealistic imagery of the body. Such generalisations fail to acknowledge the complexity of BDD development and onset, highlighting the importance of moving towards an understanding of people's implicit theories regarding their own experience. It is therefore essential to gain insight into how individuals make sense of the experiences which they believe led to the development and onset of BDD. The aim of this exploratory study was to elicit and phenomenologically analyse the accounts of individuals with lived experience of BDD in order to examine their beliefs about its origins and understand how they navigate the world with a distorted sense of self. Participants provided written and verbal accounts regarding both their BDD onset and experiences of living with the disorder. Both components of the study were analysed using Interpretative Phenomenological Analysis. Four main themes were generated from the data: *Exposure to bullying and external critique of appearance*; *Experiencing rejection, shame, and a sense of not being enough*; *Developing an awareness of the solidification of concerns*, and *Learning about and reflecting upon triggers*. Participants attributed their BDD onset to adverse experiences such as childhood bullying, receiving appearance-focused criticism, rejection and being subjected to emotional and physical abuse. The findings from this study highlight the complexity of BDD development and onset in individuals, and the need for appropriate care and treatment for those affected by BDD.

KEYWORDS

body dysmorphia, interpretative phenomenological analysis, bullying, qualitative research, BDD origins, BDD development

Introduction

Body Dysmorphic Disorder (BDD) is a debilitating mental disorder, characterised by "a distressing or impairing preoccupation with an imagined or slight defect in appearance" (Ruffolo et al., 2006: 11). The prevalence of the disorder is thought to range from 0.7% to 2.4% within the general population (Faravelli et al., 1997; Phillips, 2005; Kelly et al., 2010) and can affect people of varying ages. Typically, the average age at onset is during adolescence, at around 16 years of age (Bjornsson et al., 2013), but the root causes of the disorder remain unknown. At present, it can take up to 15 years to receive a clinical diagnosis for BDD (Veale et al., 2016: 183). Many people living with it are misdiagnosed with depression, social anxiety or social phobia (Phillips, 2005: 40), and therefore do not receive appropriate treatment. Often, people living with BDD are too ashamed to seek help, largely due to the fear of being perceived as vain (Phillips, 2005; Buhlmann et al., 2009). Recent findings regarding suicidality in BDD also discovered that people living with BDD were four times more likely to have experienced suicidal ideation and 2.6 times more likely to have attempted suicide than individuals diagnosed with eating disorders, Obsessive Compulsive Disorder (OCD) or other anxiety disorders (Angelakis et al., 2016: 61). It is therefore important to increase awareness of this under-researched disorder, and amplify the voices of people who live with it. Accounts of the lived experience of people living with BDD and its origins are lacking in academic research, and it is essential to understand the condition better through people's experiences, helping to provide earlier diagnosis and design acceptable and appropriate services. In order to do this, we must understand how it can develop and in what circumstances. With regard to the identification of potential contributing factors of BDD development, this is still an area that remains unclear and under-researched across the literature. It should be noted that, as yet, there is no definitive set of events that are 'proven' to contribute to the development of BDD. Researchers have suggested that there may be numerous predisposing factors that have influence over the development, or triggering, of the condition. Some of these proposed factors include genetic or hereditary implications and physical differences in brain structure, such as differences in regional brain volumes (Buchanan et al., 2014), and reduced cortical thickness (Grace et al., 2017) in comparison to healthy control groups. Neziroglu et al. (2004) proposed a biopsychosocial model for the examination of the presence of environmental influences of BDD development. Their biopsychosocial model takes into account external stimuli including cultural beliefs and values, life events and social influences (Neziroglu et al., 2004) as well as the neurobiological and evolutionary factors that may be associated with the development of BDD. According to this model, some of the key social and environmental influences or risk factors that may lead to or trigger BDD include pressures from society to be 'perfect' due to cultural beauty standards, and aesthetic sensitivity.

Despite emerging interest in BDD research, the majority of the research is quantitative. Therefore, there is still very little understanding of the personal, idiographic experiences of those living with the disorder. Of the qualitative BDD research available, studies have found that there are notable inconsistencies between the ideal and actual selves of those living with the condition (Silver et al., 2010; Silver and Reavey, 2010; Brohede et al., 2016). Silver and Farrants (2015) conducted a qualitative study exploring BDD participants' experiences of mirror gazing using a combination of photo elicitation and Interpretative Phenomenological Analysis (IPA; Smith, 1996). Their study considered the motivations of individuals with BDD who engaged in mirror gazing and provided rich insight into the phenomenon; however, the study focused on one specific manifestation of BDD, rather than exploring multiple facets of the disorder. Weingarden et al. (2017) published a mixed-methods study investigating triggering events that patients believed contributed to their development of BDD. This study involved analysing the self-identified triggering factors of 165 adult BDD patients, and it was suggested that the most common events contributing to the emergence of BDD symptoms described in their narratives were experiencing bullying, abuse and family stress. Although this study collected data from a large sample size and gave a good idea of the scope of events people with BDD may attribute to the disorder, it did not explore the significance in meaning of those events to the individuals. For example, the descriptor 'family stress' is vague, and it is unclear what the respondents' experience of family stress involved, and how they believe it may have triggered their BDD.

To gain more clarity with regard to the lived experience of BDD and what individuals believe the origins of the disorder to be, we have drawn on concepts of phenomenology and psychological literature to make sense of our findings. Phenomenology is "a philosophical approach to the study of experience" (Smith et al., 2022: 7). We employed Interpretative Phenomenological Analysis (IPA; Smith, 1996) to "understand and 'give voice' to the concerns of participants" (Larkin et al., 2006: 102). To the best of our knowledge, this is the first paper to use IPA as a methodological approach to explore the accounts of people living with BDD regarding both its possible origins and experiences of living with it. Through our analysis, we generated four main themes: *Exposure to bullying and external critique of appearance*; *Experiencing rejection, shame, and a sense of not being enough*; *Developing an awareness of the solidification of concerns*, and *Learning about and reflecting upon triggers*.

Materials and methods

Approach and design

In this study, we used Interpretative Phenomenological Analysis (IPA; Smith, 1996). IPA is a methodological approach used to gain deep insight into the lived experiences of people, with a focus on how they experience and make sense of phenomena. This study is a qualitative and exploratory design with a phenomenological focus. Phenomenology is concerned with "describing the world as it appears to people" (Langdridge, 2007: 11), and is therefore a useful approach to consider the way in which we understand the world through our own perception. In this study, we were interested in finding out how people made sense of the origins of their BDD. In particular, we were interested in identifying instances where participants reflected on their experiences and reflections with regard to their earliest memories of their BDD development.

Sampling strategy and recruitment

We sought to recruit participants who were aged 18 or over, and who identified as living with BDD. The recruitment process began once ethical approval was gained from the Aston University Health and Life Sciences Research Ethics Committee (Reference number: 1355). The first author circulated a study advertisement on Twitter. The advertisement was also shared by the Body Dysmorphic Disorder Foundation (BDDF) on Twitter and on their website.[1] Interested participants were invited to contact the first author *via* email to request a participant information sheet and link to a screening questionnaire hosted by Qualtrics containing a box for them to confirm they were aged 18 years or over, the Body Dysmorphic Disorder Questionnaire (BDDQ) and a consent form. The BDDQ was used as a tool to screen in people with BDD. It asks participants structured questions about how they feel about their appearance at the time of completion.

Participants

Sixteen potential participants responded to the advertisements. Of those 16 participants, eight subsequently took part in both components of the study.

Inclusion was not dependent on a clinical diagnosis but participants' own identification as someone living with BDD, given the difficulty in gaining a diagnosis. Some participants were in the process of being referred for diagnosis at the time of their interview.

Two participants identified as male and six as female. Six participants lived in the United Kingdom, one in the United States and one in India.

Data collection procedure

Data collection consisted of two parts: a biographical writing task and an interview.

Biographical writing task

First, we asked participants to complete a biographical writing task in which they were asked to write about the first time they experienced negative feelings about their appearance. They were emailed the same question and prompts to help them answer the question. Answering the prompting questions was optional, and the structure of the written piece was entirely at the discretion of the participant.

Participants who were eligible to take part in the study were sent an email from the first author within 3 days of completing the screening questionnaire, inviting them to answer the following question in their biographical writing task:

Can you tell me about a time when you first became worried about your appearance?

Some other prompts to consider:

- *What was going on in your life at the time?*
- *Did you speak to anyone about it at the time? If you did, who did you speak to?*
- *How were you feeling?*
- *What were you thinking?*
- *What did you do about it?*

Eliciting written descriptions from participants prior to conducting interviews enabled us to gain insight into their individual worlds to then facilitate the interview that followed. Using experiential material, such as the combination of written descriptions and interviewing permitted us to move away from the dominant use of interviews alone, frequently used in qualitative research.

Interview

Once participants had completed their writing tasks, we invited them to take part in a follow-up semi-structured interview to explore what they had written in more depth. A semi-structured interview follows an interview guide, "which structures the course of the interview more or less tightly" (Kvale and Brinkmann, 2009: 130). Semi-structured interviews are commonly used in IPA studies as a way of collecting data (Smith, 2016), and are developed to be flexible and led by participants.

The first author conducted all of the interviews. They lasted, on average, 68 min. Participants were given a choice of interview media (see Table 1). Eight participants completed both the biographical writing task and interview components of the study. Two participants requested their interviews were conducted *via* email, and the remaining six were conducted *via* Skype audio, telephone or Skype video.

We based our semi-structured interviews on the content of participants' biographical writing tasks. This meant participants had some control over the content of the interview. The interviewer reminded participants that they did not have to answer any questions they were not comfortable answering. In line with the flexibility of semi-structured interviews, the interviewer asked questions directly related to the accounts participants provided in their biographical writing tasks and adapted the order of questions. Once questions about the writing task had been asked, the interviewer also asked questions about their current experiences of living with BDD for additional context (Table 2).

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[1] www.bddfoundation.org

Data analysis procedure

The first author transcribed each audio interview verbatim and assigned pseudonyms to all names of people and places mentioned. When coding the data, we were particularly interested in participants' use of figurative and descriptive language with regard to understanding what they identified as contributing factors towards the development of their BDD and how they made sense of their experiences, as recommended by Smith et al. (2022). The first author coded the data, and the codes were discussed in supervision with the second and third authors. The first author proposed the initial thematic structure, which we discussed and further developed through supervision.

Analysis

Through our analysis, we generated four themes: Being exposed to bullying and critique of appearance; Experiencing rejection, shame and a sense of not being good enough; Becoming aware of the solidifying of concerns; and Learning about and reflecting on triggers. The first theme of interest was 'Being exposed to bullying and critique of appearance', which caused great distress to a number of participants in the study.

TABLE 1 Participant demographics.

Pseudonym	Age at interview	Sex	Location	Interview medium
Angelina	28	F	USA	Email
Bethany	53	F	UK	Telephone
Claire	32	F	UK	Telephone
Elliot	44	M	UK	Telephone
Jenny	34	F	UK	Skype (Video)
Kate	20	F	UK	Telephone
Rohit	28	M	India	Skype (Audio)
Victoria	18	F	UK	Email

Exposure to bullying and external critique of appearance

Experiencing appearance-focused bullying and criticisms of appearance from a young age was reported by participants as a potential origin of their BDD. The criticisms were often made by peers, friends and family members, and in most cases, the aspect of the appearance that received the criticism went on to become an area of concern and distress for the participant. Criticisms were often extensive and were not limited to one aspect of the participants' appearance.

Such criticisms were experienced by Angelina, who shared her experience of being bullied during her childhood and discussed how the same criticisms of her appearance continue to affect her in adulthood.

> It was around the time of 3rd or 4th grade [aged approximately 8–9 years] that I started to experience bullying, which usually consisted of insults and ridicule directed towards my appearance. I was literally verbally "attacked" from head to toe; my hair, my nose, my moles, my body hair, my weight and size, my "lack of curves"… Even though I tried to hide it and act unbothered by them, these comments cut me to the core and I stored them deep within the corners of my brain, ruminating on them even to this day. (Angelina, Biographical writing task)

TABLE 2 Indicative interview topic guide.

Example questions	Prompts
In your written description, you told me about [x]. Please could you tell me more about this?	• How were you feeling when you were going through this? • What was that like? • What support did you have at that time? • How were you feeling when you wrote about this? • How do you feel about this now?
(In a face-to-face interview/ Skype video interview) If I had not met you, and we had only spoken on the phone, how would you describe your appearance?	• How do you feel when you think about your appearance? • What do you like about your appearance? • What was it like to describe your appearance?
If I asked your friends, how would they describe your appearance?	• What descriptors would you agree/disagree with and why? • What support do your friends offer? • How do you feel when they do/say this? • What do you think your friends see when they look at you?
Could you describe how your feelings about your appearance have changed over time?	• Have your thoughts changed? How? • Do you do anything in your daily routine that changes the way you feel about your appearance? • Would you change anything? • What do you like the most about your appearance?

The criticisms she received from her peers targeted numerous aspects of her face and body, and were extensive and unremitting in nature. The amount of criticisms she received may have contributed to her feeling overwhelmed by the negative perceptions other people had ascribed to her body. By using evocative words such as "insults," "ridicule" and "attacked," Angelina helps us to realise how adverse these incidents of bullying were for her. She described hiding her true feelings towards what the bullies said to her at the time by pretending that their comments did not bother her; however, her distress was palpable as she revealed through a powerful metaphor that they "cut [her] to the core." The word 'cut' demonstrates just how damaging those criticisms were to Angelina, and how, in her view, the words of her bullies were weaponised. Her words "I stored them deep within the corners of my brain, ruminating on them even to this day" convey the tormenting reverberations of the painful bullying experience she endured, and continues to endure. Bullying was also considered a contributing factor towards BDD development by Kate.

> Well I've-I've-I've been bullied since I was in year three up until year eleven [aged approximately 7-16 years]… I would have people telling me I look weird… I had people anonymously messaging me and saying that I look like a dog… saying that I'm ugly… I felt hurt that people would actually say it… but at the same time I was like 'yeah you're right'… 'yeah I know I'm that – I just wish I wasn't' (Kate, Interview)

The comments Kate received from her peers occurred over an 8-year period of bullying. Being told that she looked 'weird', 'like a dog' and 'ugly' likely instilled the belief within her that something was truly wrong with her appearance, further illustrated by her coming to accept this and agreeing with the comments made. In a similar way to Angelina and Kate, Elliot experienced others commenting on his appearance at a very young age and described a scenario that took place at his school.

> When I was at school, aged approximately seven, I was sitting at a table with another boy… and two girls… one of the girls said something like 'you have lots of beauty spots' in a pleasant way referring to facial moles I had/have… [the boy], who also had facial moles, said something like 'they're not beauty spots, they're moles' in a very harsh and disparaging way… I don't recall openly reacting in any specific way. But I think it was quite soon after that I tried to dig a mole on my right forearm out with a sharp stone in the playground… I also tried to dig a mole out of the rear of my thigh, but that was not successful. (Elliot, Biographical writing task)

Here, Elliot described being in a situation where an aspect of his appearance was brought to the attention of himself and others in a negative and extremely exposing way. He recalled internalising his reaction to a situation that, upon reflection, affected him significantly. Elliot acted on the criticisms of his appearance by engaging in self-surgery in an attempt to remove the aspect of his appearance that made him seem different to others and thus vulnerable to criticism. Using a stone from the playground to perform this action shows how desperate he felt in the situation to find a solution to the negativity he experienced.

In this theme, participants described experiences of being shamed or bullied. They described those experiences as being salient to them years after the incidents had occurred. Participants also perceived themselves as inferior and unequal to the people making the bullying comments and reported that this may have contributed to the development of their BDD.

Experiencing rejection, shame, and a sense of not being enough

In addition to bullying, experiencing social difficulties in relationships was also thought to be a potential contributing factor towards BDD development. Some participants recalled being exposed to rejection in romantic and familial relationships. The rejection and sense of not being deemed good enough led to an increased concern about appearance and consequently contributed to the development of thoughts associated with BDD. This is illustrated by Claire, who described a scenario in which she experienced rejection from a friend who she considered quite important to her at the time.

> I do remember in detail how he teased me that he found my sister attractive and I tried (very poorly on reflection) to flirt with him by stating that 'I am always told that we both look alike so that must mean that I am attractive to [sic]?'… I distinctly remember the pause, the awkward laugh and the comment 'No, not really'… it is vivid in my mind during and after the phone call I was staring in the mirror… (Claire, Biographical writing task)
>
> I remember feeling quite um crushed and almost erm taken aback really a bit in shock… it felt like the bottom of my stomach had fallen out (Claire, Interview)

This humiliating experience prompted increased self-scrutiny within Claire, evidenced by her recollection of specific bodily actions such as looking at her reflection in a mirror after the conversation with her friend had ended. She described feeling 'crushed', which powerfully illustrates the force the rejection and anguish had on her body. This subsequently led to Claire manifesting these emotions in the form of physical bodily sensations: "it felt like the bottom of my stomach had fallen out." Another participant, Jenny, also identified a link between experiencing rejection throughout her teenage years and subsequent BDD development.

> During the period between the age of 12-16 I remember being rejected by a few boys and I do think that was a contributing factor. Overall, I was heavily comparing myself to others and idolising girls who were slim and pretty. (Jenny, Biographical writing task)

Jenny made a link between being rejected and comparing herself unfavourably to others. In this excerpt, she identified that multiple rejections, in combination with her preconceived notion of what is and is not considered "pretty," reinforced the perception that she was defective and inadequate compared to her peers. During this time in her life, she described making direct comparisons between her own appearance and the appearance of others she considered to be more desirable. However, not all criticisms and comparisons she reported were related to her appearance. Jenny also faced physical abuse as well as hurtful comments and observations from family members about the way she behaved.

> My dad would get short tempered with me and tell me off, although I don't remember the details, I just have a sense of not feeling good enough in his eyes so whatever was said created that belief in me. He once hit me (slapped across my face leaving a hand print) because I did something wrong and I remember the moment clearly, although I have no idea what I did wrong. I also got told repeatedly when I was naughty or annoying that 'I was so much like my auntie [name redacted]' who was viewed very negatively by the family. (Jenny, Biographical writing task)

She described being physically abused by her father for reasons that remain unclear to her, and being directly compared to another family member who was not well liked. In a similar way to Jenny, Rohit experienced many criticisms and comparisons from a family member during his childhood that focused on his behaviours rather than his physical appearance.

> She [Rohit's mother] had an abusive nature, was harshly critical and discouraging towards me. She would keep pointing out mistakes and negatives in me and everything I did. She used foul language and cursed regularly. I do not remember being appreciated or encouraged for anything by her. I remember getting shamed often, in comparison to other kids of my age, my cousins and friends. I received verbal abuse often for the mistakes I made, even simple things like buying the wrong vegetables from the shop. The words were ugly very often. (Rohit, Biographical writing task)

Being shamed and harshly criticised by his mother may have left Rohit vulnerable to developing a poor relationship with his own sense of self during his formative years, which would shape his self-identity as he grew older. Rohit described his mother's abusive character and reflected on the comparisons drawn with other children his age. We might speculate, by his detailed description, that Rohit's experience of his mother may have affected his self-concept. Experiencing a lack of appreciation and encouragement from a young age is likely to cultivate negative evaluations about one's sense of worth. These negative evaluations of the self could then manifest as an overall sense of not being good enough. As the negative manifestations of the sense of self-built up, participants discussed becoming more aware of concerns about aspects of their physical appearance.

Developing an awareness of the solidification of concerns

Some participants reported having a poor relationship with their appearance from a young age prior to their BDD onset, but this relationship deteriorated further over time and they noticed concerns solidifying and becoming more 'real' or concrete to them. This shows one potential way the disorder may develop in some people. It is possible that Victoria may have experienced concerns about her appearance from a young age due to her receiving critical comments about her appearance at school, but describing aspects of her appearance as 'deformities' is symptomatic of BDD.

> … when I started sixth form I became even more concerned with my appearance and I started to feel as if my flaws were deformities…
>
> I think I found an article about it [BDD] once and it sounded like me or something like that happened I'm not sure. But it sounded like what was happening and I didn't really know wether [sic] I actually had it or wether [sic] I was being a hypochondriac but I must have it or I'm really hideous and I'm using it as an excuse for my horrible face. It made me feel kind of good that other people had it and I started to read about it more and it would always make me feel sad and I also felt like I didn't have it because everybody else with it was actually quite pretty and I'm not pretty enough for it to just be my brain lying about a couple of things because it's not that it's my actual face being ugly and deformed. (Victoria, Interview)

Victoria appears to express doubt that she has BDD and convinced herself that her perceived flaws were objectively real. She described a tension in her belief of having BDD and not having BDD. The doubt she dwelled upon regarding whether she has BDD appears to be due to the inseparability of her perceived self and objective self. In other words, her perceived distortions are irrefutable, in that she does not consider them to be distortions. She alludes to this idea by using the phrase "my horrible face." By describing her face as "horrible," she attaches her distorted perception to her objective appearance, reinforcing their inseparability. She additionally uses words such as 'hideous', 'ugly', and 'deformed' to describe her appearance, conveying how realistic the distortions are to her.

Like Victoria, Claire described the foregrounding of her appearance concerns becoming more concrete and problematic during a specific time period.

> The longer I looked [in the mirror] the less it made sense what I was looking at… the features seemed to be much more individual rather than looking at a face as a whole…
>
> I don't see a face as such – I just see faults (Claire, Interview)

Seeing her face as a series of characteristics, or 'faults', illustrates the atomistic behaviour that Claire and many others living with BDD experience. Breaking the face down into its constituent parts and not being able to see the whole picture any longer is characteristic of BDD.

Claire momentarily brings our attention to the temporal domain when viewing her appearance in the mirror. She makes a link between the prolonged duration of time spent looking at her appearance and a sense of ambiguity regarding the focus of her gaze she experiences whilst doing so. She described a scenario in which she began to focus on parts of her face in isolation rather than appraising her whole face. This could be interpreted as a gradual process in which she (over a period of time) experienced the separation and possible foregrounding of her perceived problematic features, and a lack of cohesion between them. This supports the idea of appearance concerns solidifying and becoming more apparent to the perceiver over a length of time.

By contrast, Elliot made sense of his BDD onset differently. Unlike other participants, Elliot described the onset of his BDD symptoms as occurring quite suddenly, rather than a gradual increase in tangibility and becoming more real over time. He did not attribute the onset to a particular event or series of events, but he did acknowledge having a problematic relationship with his appearance previously. He spoke about a specific moment in his life when he recalled suddenly not being able to look at a particular aspect of his appearance.

> I think BDD really kicked in when I went to university. I think the first real problem I had was looking at the left side of my face. (Elliot, Biographical writing task)
>
> I probably already had-had quite erm an unhealthy relationship with my appearance in a way-but just-it just sort of-I just remember thinking-there was just one day I couldn't er I just couldn't cope with looking in the mirror and seeing the left hand side of my face [and] just… just- just-it just sort of – you know – just-just really happened… erm and then it was really-yeah I dunno it just seemed to happen – it wasn't sort of-I think it may have just been er the overall pressures of being in that situation – not really being… having the resources to deal with it – it wasn't like – you know – any-it wasn't- I don't recall it being anything specific (Elliot, Interview)

Using the phrase 'kicked in', suggests Elliot experienced a sudden and notable change in the way he viewed himself. Specifically, the change affected his perception of the left side of his face. Like Claire, Elliot displays the atomistic behaviour characteristic of somebody living with BDD as he identifies the specific area of his face he struggles to view. It is apparent in Elliot's communication that recalling this significant phenomenon was difficult to express with language. The amount of effort he put into explaining the phenomenon is very apparent with instances of self-correction and hesitancy. Reflecting on his realisation of BDD becoming more apparent to him, Elliot explained: "… one day I couldn't… cope with looking in the mirror and seeing the left hand side of my face… it just… happened." His reference to coping in this excerpt is particularly interesting. Elliot may have been able to pinpoint his onset by reflecting on his capacity to cope with appearance-related events leading up to and after that day. It is evident that this day was significant to him, as he is able to recall a time when a part of his life changed, but he cannot express what he believes may have caused it.

Accounts from participants about how they make sense of their appearance concerns solidifying suggest that the rate of BDD onset could vary. It could develop over a period of time or occur quite suddenly. There appears to be a 'tipping point' where participants are able to come to a realisation that their relationship with their appearance is not typical, and it may be this point that participants remember more clearly. Some participants were able to identify specific circumstances that made them think about their appearance concerns more often, and this was an important step in their reflective process.

Learning about and reflecting upon triggers

An important element of understanding the origins of people's BDD is understanding what people believe their BDD triggers to be. Whilst the triggers may not directly reveal specific origins of the disorder in participants, they help us to gain an understanding of what could worsen BDD in people who live with it, and potentially, how it could be managed. In taking part in the study, participants were able to reflect on the triggers that affect them presently as well as in the past, providing some insight into what they struggle with. Angelina reflected on thoughts she experiences presently with regard to her BDD triggers.

> I do have certain triggers that definitely bring them [the thoughts] on, such as if I run into a person I went to school with, if I see a picture of myself that I don't like or when I look at old pictures; but for the most part the thoughts ARE the triggers and they truly never stop. (Angelina)

Angelina conveys a sense of ambiguity between whether the thoughts she experiences as a result of BDD are triggers or symptoms of BDD. She identified specific events that act as catalysts, leading her to think about the adverse experiences of appearance-focused bullying she went through which subsequently contributed to the development of her negative perception of her appearance. She also acknowledged that her thoughts are continuous throughout her everyday life regardless of the possibility of those triggering events occurring. Like Angelina, Bethany was able to pinpoint specific situations in which her BDD worsens but also highlighted its omnipresence.

> My BDD flares up considerably whenever I am stressed or anxious but even when I am not, it is there with me constantly every day… you asked how often I thought about my body image and I can honestly say that it would be impossible to say because it feels like the thoughts are there almost all the time. It would be easier to let you know how often I don't think about it. It is quite often my waking thought and I dream about it regularly. (Bethany, Biographical writing task)

From Bethany's description, experiencing heightened negative emotions such as stress and anxiousness led her to become more concerned about her perceived flaws in her appearance. However, it is clear that her experience of BDD immerses her lifeworld. Whilst she portrays BDD as being a separate entity, she suggests it is very much fused to her body and self: "*it is there with me constantly every day*." Due to its perceived permanency, it is difficult for Bethany to identify where BDD begins and ends. It is a constant phenomenon woven throughout her life, and she highlights that it is easier for her to isolate thoughts that are *not* associated with her negative body image.

Victoria was also able to reflect on triggers that worsen her BDD symptoms and identified particular incidents that amplified her negative perception of self. Examples of this included times when her confidence was knocked by a boy (this might include receiving criticisms of appearance or experiencing rejection) or when she, like Angelina, viewed a photograph of herself that she considers unattractive.

> When a photo is taken of me I have to spend ages looking at it and it makes me feel disgusting and I feel disgusting now thinking about different photos I've looked at with me in. I look deformed and it makes me worry because I must look that vile in real life and I try to look at what individual features are the problem but it's all of them… it's something that can't be fixed easily or can't be fixed at all. I always notice new features I hate in photos. (Victoria)

Here, Victoria described how viewing a photograph of herself that she considers unattractive can cause elevated and prolonged feelings of worry and concern. Additionally, experiencing a sense of compulsion is conveyed when she explained specific ritualistic behaviours she exhibits: "I have to spend ages looking at it [the photograph]." This demonstrates that she feels compelled to inspect the photographs due to her BDD. She experiences a feeling of disgust if she does inspect a photograph of herself, and this disgust is also evoked by memories of her appearance in photographs too, suggesting she may be haunted by residual distortions. Whilst Victoria was describing her feelings of disgust when viewing photographs in her interview, she said she felt disgusting in that moment "*now* thinking about different photos I've looked at with me in" (emphasis added). This could convey how ingrained the images of her perceived self are; she is able to imagine them vividly enough upon thinking about them to physically feel nauseous. Victoria finds viewing photographs of herself particularly disturbing as they reinforce her perceived view of her appearance due to them being thought of as concrete objects that truly represent the subject matter they show: "it makes me worry because I must look that vile in real life." This then leads her to attempt to localise the features that cause her disgust, but instead, she identifies new areas of concern in the process, and this torturous cycle continues.

Discussion

This section will attempt to theorise the self-identified origins of participants' BDD by drawing on phenomenological concepts and psychological literature. We will demonstrate how a phenomenological perspective can be valuable in helping us gain a richer understanding of possible origins or contributing factors towards the development of BDD from individuals who live with the disorder and potentially aid their care and treatment. In the remainder of the discussion, we will draw on the work of Merleau-Ponty, a phenomenologist known for his contributions to understanding bodily perception and consciousness. We will also draw on Sartre and Heidegger's work to reflect upon issues of interacting with the world and existentialism.

The data presented in this study illustrate the varied ways that individuals living with BDD believe the disorder developed for them, ranging from experiencing appearance-focused bullying, rejection, shame, sudden onset and the solidifying over time of perceived defects. To make sense of the events contributing to the development and onset of their BDD, participants employed imagery, for example, of being attacked by words, feeling strong bodily sensations and vivid descriptions of self-surgery, for example.

Due to the body being affected by the events described by participants, it becomes a focal aspect of their experience as the development and manifestations of the disorder are lived through their bodies. Very often, the body is treated as a biological object in psychology, but the body is also a social object (the means by which our identities are 'read' by others) and a perceiving object (the means by which we understand the world, and the people in it). Merleau-Ponty has written in great depth about embodiment in relation to perception and the social world. He suggests that our bodies are central to our ability to experience and understand the world and are interwoven with our perceived world (Merleau-Ponty, 1945/1962).

Through a phenomenological perspective, we are able to access and pay attention to the subtle nuances of individual phenomena expressed by participants and better understand from where and how the onset of BDD may originate. Living with a disorder such as BDD can greatly affect an individual's 'being-in-the-world' (Heidegger, 1927/1962), as the relationship with one's body is disrupted and the interface with one's world is affected.

The disruption of a participant's being-in-the-world is exemplified by Angelina's account of experiencing appearance-focused bullying. Bullying was identified as a potential contributing factor of BDD development by several participants in our study. In addition to this, Weingarden et al. (2017) found that bullying was the most commonly prevalent experience reported by BDD patients, further suggesting that receiving criticisms of appearance may be linked to BDD onset. Having many parts of Angelina's appearance extensively criticised and mocked by her peers may have directed her concerns on those aspects and therefore changed the way she views her existence in the world. This situation is reminiscent of being *othered* (Wilkinson and Kitzinger, 1996), as she is made to feel inferior to her peers, reinforcing her perception that she is different to the larger social group. Similarly, Elliot may also have experienced othering when his moles were pointed out by the children in his class. This interaction led him to make the decision to engage in self-surgery in an attempt to remove the moles from his body using "a sharp stone in the playground," thus removing the very object that caused him to be othered in that situation. Elliot taking the stone and using it as a tool to alter his body could be described as a fulfilment of Heidegger's (1927/1962) concept 'readiness-to-hand' which "captures the serviceability or usability connotations that belong to the very being of implements" (Stapleton, 2010, cited in Davis, 2010: 51). Elliot's motivation to radical self-deforming action conveys his strong desire to change his body. He viewed the stone as a tool that could help him remedy the problem he had with this particular aspect of his appearance, and the use of such an unsuitable item highlights the sense of agonising desperation he felt in that exact moment. Elliot's altering of his appearance could also be likened to him viewing his body as a 'body project'. Placing emphasis on one's body and adapting our appearance for public display turns our body into a 'project' (Nettleton and Watson, 1998: 1). Shilling (1993) states that "the body might best be conceptualised as an unfinished biological and social phenomenon, which is transformed, within limits, as a result of its participation in society" (Shilling, 1993, cited in Nettleton and Watson, 1998: 7). When viewing Elliot's body as a project, we can consider the possibility of him altering the appearance of his body due to his want to be accepted as part of his social group and being objectified under their critical gaze.

Sartre noted that, as humans, we become aware of ourselves when we are viewed by others. It could be due to this sense of 'bodily vulnerability' (Dolezal, 2017: 423) that Elliot became more aware of his moles during the event he describes. The fact that he attempted to change a part of his physical appearance subjected to critical gaze suggests that, from this moment, he was no longer unconscious of his appearance (being-in-itself; Sartre, 1943), but now aware of his own appearance and others' perception of his appearance, and wanting to adjust it in response to the criticisms (being-for-itself; Sartre, 1943). In psychological literature, there is some evidence to suggest that a number of people with BDD 'dissociate' or feel betrayed by their bodies. For example, they may experience thoughts such as "'the way my face/body looks made this happen to me. My body betrayed me therefore I hate my body'" (Constantian, 2019: 119). It could be said that some people with BDD who receive criticisms about their appearance from others in the same way that Angelina and Elliot have may feel betrayed by their appearance and resort to self-surgery or self-harm. The behaviour that Elliot describes is in line with findings from Veale's (2000) study, in which he highlights the fact that people with BDD may engage in self-surgery, or 'DIY surgery', in order to alter their appearance without going to a surgeon. This often has disastrous effects on the individual and can worsen BDD symptoms.

Rejection, shame and a sense of not being good enough were fundamental experiences to participants living with BDD. Previous literature has explored the relationship between shame and BDD (Weingarden et al., 2018); however, the personal lived experience of participants was not explored. Instead, participants' shame was measured using the Young Schema Questionnaire-Short Form. In Weingarden et al.'s (2018) study, shame was presented as an internal emotion experienced by people living with BDD as a result of their BDD and concerns about the way others may view their perceived flaws. However, it did not address other potential sources of external shame such as bullying and rejection, which played important roles in the lives of participants in this study. As a consequence, we argue that future studies of BDD should incorporate clear and robust methods for thinking about the dimension of shame. Sartre described shame "as central to the ontology of human existence" (cited in Dolezal, 2017: 421). All participants reported several events that led them to feel a sense of shame. In most cases, the events were directly linked to the participants' physical appearance, but there were some exceptions.

Heidegger (1927/1962) put forward the idea that we often take our bodies for granted, and only become aware of our bodies when we become ill or experience a feeling of pain or discomfort. It is possible that being subjected to an external source of shame may lead a person to become aware of bodily concerns. However, a person with BDD may perceive this critiqued image of their self as being concrete and completely real to them, thus reinforcing their belief that their appearance is defective. This may have been the case for Claire, who stated that she only saw individual "faults" rather than her whole face when she viewed herself in the mirror after experiencing rejection and criticism of her appearance. Victoria also talked about elements of her appearance transcending concern and becoming 'deformities' for her. It was noted by Veale and Riley (2001) that as individuals with BDD looked in the mirror, they became increasingly self-conscious and their negative perceptions of themselves were reinforced, which further elucidates Claire's and Victoria's experiences. Further to this, a clinical eye-tracking study by Greenberg et al. (2014) examined attention bias in people with BDD and a healthy control group and found that the BDD group focused on features on their own faces that they considered unattractive when viewing photographs of themselves. This finding is in line with participants from our study who often reflected on being preoccupied by specific areas of concern in their appearance when viewing themselves in mirrors or photographs. These areas of concern were often linked to criticisms made by others.

As well as participants receiving criticisms of their appearance, non-appearance related criticisms were also of interest. The experience of being criticised for behavioural aspects of the self was talked about by Jenny and Rohit, who both recalled receiving physical or verbal abuse from family members at a young age. Recent findings from Constantian (2019) suggest that childhood abuse may be linked to the experience of feeling ashamed of one's body, as it 'imparts a sense of vulnerability, fear, and helplessness' (Constantian, 2019: 139). In addition, it has been argued that all types of abuse are tied to the body 'by inflicting fear or pain, denying needs, or negating the importance of the individual' (Herman, 1992, cited in Constantian, 2019: 140).

Participants additionally reflected on what their self-identified BDD triggers were at the time of interview and we felt this was an important step towards finding out what may contribute towards or worsen BDD symptoms. The triggers were varied, and all posed a substantial threat to the wellbeing of the individual. Angelina's triggers include crossing paths with people from school and viewing photographs of herself that she does not like. This example is reminiscent of embodied knowing (Merleau-Ponty, 1945/1962), in which the world foregrounds the body. In this instance, elements of the external world (people from Angelina's school or certain photographs) draw Angelina's attention to the parts of her body she is affected by as a result of reminders of the harsh criticisms she faced and still associates with them, in a similar way that knowledge and experience can be 'imprinted' on one's body (Tanaka, 2011, cited in Stenner et al., 2011: 149). She alludes to a cyclical relationship between experiencing BDD thoughts and triggers, making it difficult for her to separate the two and establish what is worsening her BDD. Weingarden et al. (2017) found that participants in their study 'actually recalled an early experience of a BDD ritual, rather than the trigger of their BDD onset itself' (Weingarden et al., 2017: 23), highlighting the difficulty in differentiating rituals and triggers. However, not all participants named specific triggers that worsened their symptoms. In addition, the rumination that Angelina describes may be further explained by a finding from Osman et al.'s (2004) study, which stated that people living with BDD who were bullied often experience spontaneous memories of the bullying and teasing that took place.

It is clear from the participant data that BDD is all-consuming and affects the lifeworld of those who live with it. As Bethany states, *"it* [BDD] *is there with me constantly every day."* She acknowledges that it is a part of her life, that is, she lives with it and is forced to adapt her being-in-the-world in order to accommodate it.

Conclusion

This study explored the self-identified origins of Body Dysmorphic Disorder (BDD) in eight participants living with BDD and how the disorder impacts their daily lives using Interpretative Phenomenological Analysis (IPA). The study identified and made sense of some potential contributing factors towards the development of BDD, such as experiencing childhood bullying and criticism, rejection and abuse. We also explored the idea of differing rates of BDD onset ranging from gradual development to sudden onset.

The misunderstandings and stigma attached to BDD are damaging to those who live with it and, in facilitating a more accessible way for individuals to display facets of the disorder, it is hoped that this study can help to raise the profile of BDD, help people become aware of its manifestations and reduce the surrounding stigma and ambiguity presently associated with it. Although there were similarities in the experiences participants shared across cases and across the study's main themes, the way each participant made sense of those experiences was entirely unique and thus provided a variety of perspectives on multiple aspects of the disorder, made possible by IPA's focus on the idiographic. There is still much more to learn about the origins of BDD, therefore more research in this area is needed in order to bring its potential beginnings, symptoms and manifestations to the attention of professionals and aid them in providing treatments and necessary support to those living with BDD. We believe using qualitative approaches such as IPA can help to gain a deeper understanding of what it is like to experience BDD from the perspective of those with lived experience of the disorder. Phenomenological research could also provide further insight into under-researched areas such as implications of rate of BDD onset, investigations into coping strategies and management of BDD symptoms, experiences of help seeking and the effectiveness of treatments for BDD. To conclude, we wish to highlight the need for professionals working with those affected by BDD to take into account the role of problematic social-developmental events, interpersonal relations and emotions with regard to how people understand their own BDD onset, moving away from previously held assumptions about the disorder. Additionally, we emphasise the importance of continuing to foreground the experiences of people living with BDD, as they currently remain vastly unheard and underrepresented in the research domain.

Data availability statement

The datasets presented in this article are not readily available because of ethical reasons. Requests to access the datasets should be directed to S-LC, s.craythorne2@aston.ac.uk.

Ethics statement

The studies involving human participants were reviewed and approved by Aston University Health and Life Sciences Ethics Committee. The patients/participants provided their written informed consent to participate in this study.

Author contributions

S-LC: conceptualisation, methodology, investigation, and writing–original draft. RS and ML: supervision and writing–review and editing. 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.

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United States

REVIEWED BY
Melissa Tamelini,
University of São Paulo, Brazil
Cecilia Maria Esposito,
IRCCS Ca 'Granda Foundation Maggiore
Policlinico Hospital, Italy

*CORRESPONDENCE
Milena Mancini
milena.mancini@unich.it;
mancinimilena@yahoo.it

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Se-duction is not sex-duction: Desexualizing and de-feminizing hysteria

Milena Mancini[1]*, Martina Scudiero[1], Silvio Mignogna[1],
Valentina Urso[1] and Giovanni Stanghellini[2,3]

[1]Department of Psychological, Humanistic, and Territorial Sciences, University "G. D'Annunzio", Chieti, Italy, [2]Department of Health Sciences, University of Florence, Florence, Italy, [3]Centro de Estudios de Fenomenologia y Psiquiatrías – Diego Portales' University, Santiago, Chile

The psychopathological analysis of hysteria is a victim of narrow conceptualizations. Among these is the inscription of hysteria in the feminine sphere, about body and sexuality, which incentivized conceptual reductionism. Hysteria has been mainly considered a gendered pathology, almost exclusively female, and it has been associated with cultural and/or religious features over time rather than treated as a psychopathological world. Further, hysteria has been dominated by conceptual inaccuracies and indecision, not only in terms of clinical features but also in terms of its definition. For this reason, it seems necessary to "undress" hysteria from this feminization, sexualization, and corporealization with which it has been abundantly clothed over the years. "Undressing" hysteria will make possible a reconfiguring and deconstructing of the explanatory-causal model of Charcot and Freud. However, if we take out this cultural heritage, the stigma accompanying this diagnosis, and the weight of the enormous historical tradition that hysteria carries, the world of hysteria continues to constitute a domain full of complexity and nosographic challenges. Hysteria has been considered a sum of psychological behaviors and states illustrated by drama, mystery, or falsity. The difficulty in understanding the multiple somatic manifestations which characterize this clinical condition created several controversies and much confusion. In the current nosography, the personological component of hysteria has been separated from its symptomatic manifestation, in the Histrionic Personality Disorder and Conversion Disorder categories, respectively. This segmentation by descriptive nosography does contribute to a unitary understanding of the phenomenon and, consequently, of daily clinical practice. Clinical complexity can be grasped and deciphered only if the symptom is inscribed in the patient's lifeworld and his/her subjective life history. Clinical practice is thus thought of in terms of a structural aggregation of a homogeneous set of phenomena, together constituting a specific way of being in the world. The starting point of this article is the evident modalities characterizing this life-world, taking care not to confuse the point of origin with the point of expression.

KEYWORDS

hysteria, desexualizing, de-feminizing, visibility, phenomenological psychopathology, subjective experience

Introduction: A short history of hysteria as a gender disorder

There is a clinical condition that throughout history has been responsible for much of the stigma associated with feminine corporeality and sexuality, known as "female hysteria" (Tasca et al., 2012; Ussher, 2013; Hooper et al., 2019; Gallic, 2021). Before its classification as a mental disorder, hysteria was considered a gender-specific physical disorder affecting individuals with a uterus. The first evidence of hysteria can be found in ancient Egyptian and Greek cultures. Hippocrates (459–376 BC), who first introduced the clinical use of the term "hysteria," believed that the uterus (*hysteron* means "uterus" in ancient Greek) could migrate around the body, pressuring other internal organs and causing several diseases (Sigerist, 1951; Trimble and Reynolds, 2016). According to ancient physicians, sexual deprivation was frequently the cause of hysteria (Williams, 2022). Symptoms associated with hysteria included swollen abdomen, suffocating angina or dyspnea, dysphagia, cold extremities, tears/laughter oscitation, pandiculation, delirium, and irregular heart rate. The treatment of hysteria involved the repositioning of the uterus through various techniques.

From the advent of Christianity until the Middle Ages, hysteria was associated with phenomena such as witchcraft and demonic possession. The mainstream view of those times conceived the woman as a physically and theologically inferior being, i.e., a "failed man," an idea with its roots in the Aristotelian concept of male superiority. Thus, women were considered sinful and defective creatures (the Latin term *foemina* means "who has less faith"). From the 13th century onwards, many manifestations of mental illness were seen as the consequences of bonds with forces of evil. At that time, the gold-standard treatment to heal "hysterical" women was an exorcism. In early Christianity, exorcism was considered a cure, but by the late Middle Ages, it had become a punishment, and hysteria was confused with witchcraft (Alexander and Selesnick, 1975).

Paracelsus (1493–1,541) considered hysteria a chorea lasciva, a lecherous or lustful dance, patently connecting it to femininity and sexuality. During the Enlightenment, sorcery becomes a matter of medical care. In the Encyclopédie, sorcery was viewed as a ridiculous activity and mental illness began to be framed within a scientific perspective. Hysteria itself was described as one of the most complicated diseases (Diderot and D'Alembert, 1968).

Throughout the 18th and 19th centuries, hysteria was one of the most commonly diagnosed "disorders." In modern medicine, hysteria was first accurately described in 1880 by Jean-Martin Charcot (1825–1893). Freud attended Charcot's lessons at the Paris hospital La Salpetrière. Building on and extending Charcot's theories, he hypothesized that hysteria was the outcome of a "psychological scar," triggered by trauma or repression, rather than the consequence of a physical injury affecting the brain (Charcot, 1998; Leoni, 2008). The highlighting of the psychic etiology of hysteria goes hand in hand with the main discoveries of psychoanalysis, i.e., the unconscious, conflict, trauma, defenses, transference, and identification (Laplanche et al., 2018). Sexuality was placed center stage. The conflict unleashed against certain sexual impulses was considered the basis of hysteria and all other neuroses. At first, Freud believed that hysteria could be explained as the effect of missing abreaction of affective charges related to the memory of a traumatic event in childhood, experiences of sexual abuse or incest in particular. Later, Freud considered that this seduction had never taken place in reality but only in the imagination, and reduced the emphasis on abuse in childhood by focussing on the sexual fantasies of the child (Lingiardi and McWilliams, 2017).

The 'father of psychoanalysis' believed that women developed hysteria because they could not recognize and overcome their castration complex. From time to time, researchers of medical history have evidenced that hysteria was a way to pathologize "everything that men found mysterious or unmanageable in women" (Devereux, 2014). Treatments for this condition ranged from pelvic or uterine massages, to forced rest, or even marriage. In severe cases, a hysterectomy was performed.

From a gender perspective, hysteria has essentially been conceived as the medical justification for men's dominance over society and medicine and a synonym supported by "over-emotional" or "unbalanced," which were deemed to be characteristics of the female gender. Simone De Beauvoir (1908–1986) wrote of the "complex" female nature, which according to many was guided by hormones, mysterious instincts, and repressed desires: "The ovule has sometimes been likened to immanence, the sperm to transcendence" (De Beauvoir, 1989). Similar gendered and sexualized stereotypes include the belief that women should be obedient, passive, moderated, and sexually inhibited. It is not a coincidence that most prescriptions for hysteria involved regular marital sex, marriage, or pregnancy and childbirth: all accomplishments for a culturally framed "proper" woman.

Borrowing Michel Foucault's (1926–1984) expression, society has always influenced psychiatry's judgment about normality or disease (Foucault, 1961). This idea is tangible in hysteria more than in any other diagnostic category (Tasca et al., 2012). In the second half of the 20th century, a "decrease" in hysteria was recorded in Western societies. In contrast, studies focused on non-Western countries demonstrated that during the same period, hysteria, as one of the somatic ways of expressing emotional distress, remained a prominent condition among psychiatric patients (Leff, 1981). Up to a few decades ago, hysteria-like phenomena were also reported in Southern Italy by cultural anthropologist Ernesto De Martino (1908–1965). He studied the phenomenon called "tarantism." In southern Apulia, people believed that the bite of a particular species of spider ("tarantula") could cause a psycho-physical disorder – a form of hysterical neurosis manifesting with body spasms and convulsions. Its "treatment" consisted of music therapy and dance sessions (De Martino, 2015). Moreover, tarantism was an exclusively female disorder.

Hysteria has been used as an instrument of power to sanction women's perceived intellectual, physical, and moral inferiority.

This controversial clinical condition was used to justify the confinement, control, and pathologization of women. Today, this attitude has apparently been overcome. However, it has taken on new forms. For example, medical operators are more inclined to describe the pain of patients with adjectives such as "emotional, psychogenic, hysterical or hypersensitive" when those patients are women (Zahang et al., 2021). Hysteria was officially removed from DSM after being used as an umbrella term to encompass numerous different symptoms, reinforcing injurious stereotypes about sex and gender. Recent nosography of hysteria was rather convoluted. In DSM-I hysteria was designated the name "conversion disorder" and in DSM-II it was termed "hysterical neurosis" (American Psychiatric Association, 1952, 1968). Starting from DSM-III, it was included among "somatoform disorders" (American Psychiatric Association, 1983). More recently, the personological (trait) component of hysteria has been separated from its symptomatic (state) manifestation, into Histrionic Personality Disorder and Conversion Disorder, respectively. The latter is also known as Functional Neurological Disorder (American Psychiatric Association, 2014). Other aspects of hysteria are located in the category of Dissociative Disorder. In this article, we focus on the histrionic personality, not on other aspects of "hysterical neuroses." Unfortunately, despite its exclusion from official psychiatric nosography, the stigma associated with this peculiar condition persists nowadays, both in clinical and non-clinical contexts.

The body in between sexuality and seduction

The body represents the most investigated dimension in the world of hysteria (Didi-Huberman, 2004; Stanghellini and Mancini, 2017, 2018). Freud (1886–1895) believed that hysteria was first and foremost a diagnosis of the body and hysterical symptoms, based on the expressive power of the body, were its "symbolic dimension," its theatricality, and its metaphorical significance. This almost exclusively bodily conceptualization of the hysterical symptoms is coherently linked to the question of femininity and sexuality. Moving in this reductionist direction, the hysteric person is a woman, particularly a woman who attempts to name herself as such through the exhibition of her body. Here, the body is the locus of the hysterical symptoms since the body is allowed to name the un-nameable (Bollas, 2001).

The body no longer represents a way to be in a dialogical relationship with the other person (Binswanger, 1942; Richin, 1989) but is exhausted in provoking an emotional reaction in the other. Stripped of its dialogical connotation, it is clothed in mannerisms, poses, and seductiveness. Its mere purpose is to seduce the other in the etymological sense (*se ducere*) of leading the other to oneself and trapping them in the kind of bond that makes any sort of dialogue impossible. The other becomes a mere spectator of a scene in which the center is occupied by the hysterical person and his/her extreme intensification of attitudes and poses. The hysterical person's body is an instrument, a mere means to capture the gaze of the other. It is an "instrumentalized" body (Blankenburg, 1998), mutable in its intense and hyper-expressive choreography. It is a spectacular representation, a performance worthy of being immortalized and remembered.

Nevertheless, if seduction – attracting the other's gaze – is the aim of the person with hysteria, sexuality is only one of the possible ways to seduce the other, just one of the manifold trajectories and not the core of the hysterical world. Sexuality is a means, not an end, in the world of the hysterical person. Seduction is not meant to catch the other on a sexual level for sexual enjoyment or sexual satisfaction. It can operate in several other domains, e.g., exhibiting one's intellectual abilities, intensifying one's suffering, or theatrically showing one's generosity.

Typical of the hysterical condition is *impersonation* (Sartre, 1943), i.e., role-playing or play-acting, embodying a given role in a self-deceptive manner that is unconscious and involuntary. Impersonation can operate in different domains. For instance, the person with hysteria can embody the role of a person affected by a physical illness, identifying with his/her symptoms as a way to gain visibility. The identification with a person affected by a physical illness is part of so-called somatoform disorders, the cause of which can be traced back to an incapacity to "mentalize" emotional distress (PDM) and the need to gain attention by playing the role of the sick person. The fact that the hysterical person does not do it consciously and voluntarily suggests that (s) he, to lie to others, is forced to lie to themselves. This is not a deliberate fiction but an extreme self-deceptive attempt to exist. For the hysterical person, being perceived, seen, and heard is an indispensable condition for being in general: *esse est percipi*, being is being perceived.

Seduction is thus a means to recognition (Stanghellini, 2016). We can argue that the hysterical person experiences a "manque d'être" (Sartre, 1943) – a lack of being. Experiencing a constant feeling of hypo-sufficiency, (s)he depends on the other to obtain a consistent sense of selfhood and identity. From this perspective, seduction is instrumental for recognition, and recognition is instrumental for gaining a sense of selfhood: when (s)he manages to catch the other's gaze, the hysterical person feels that he/she exists, and his/her feeling of inadequacy and insufficiency vanishes. The logic of the hysterical world follows the motto *seduco ergo sum*. Seduction in the hysterical person's world is the visual power to be recognized by the Other, a device of self-recognition whose aim is to construct a sense of selfhood and defeat hypo-sufficiency. The hysterical person aims to achieve a "consistency of being" in which (s)he can experience the gratifying feeling of "being special" to the other. The aim is not to dominate the other, but rather to bring the other as close as possible to oneself to feel visible. Putting the hysterical persons' need for recognition center stage strips them of the gender and sexual aspect with which they have been clothed over time.

Two modes of seduction can be preliminarily traced from here. The first is the intensification of one's attitudes and feelings, defined by Charbonneau (2007) as "figurality." The other is placed on a pedestal, and every his/her attitude, word, and posture have the aim of being admired by the idealized other. The second mode of capturing the other's gaze is *via* self-victimization and infantilism with the aim of being cared for by the other. Both modes have in common the aim of keeping the other available and attentive, capturing and keeping their gaze fixed on oneself as compensation for one's feelings of hypo-sufficiency.

Visibility as the core of seduction

The dismantling of the predominant idea of sexuality in the hysterical world and the primacy of seduction brings out another characteristic: visibility. Throughout history, hysteria has been sorrow reinvented as spectacle and an image. Everything that produces passion in the soul pushes the body to some form of action or expression. Hysteria is nothing more than a sentimental experience: soul affections become bodily catastrophes, an enigmatic and violent manifestation of otherwise invisible feelings. The symptom ("What do you feel?") becomes a visible sign, and the diagnosis becomes a skillful interpretation of what is visible when armed with photography. Photography brought hysteria center stage at the end of the 19th century. In Charcot's time, hysterical patients were shown to an audience of doctors and photographed. This indulging in their gaze allowed the persons with hysteria not to be relegated and forgotten in the pavilion of the "Incurables." The only way they could avoid being neglected was to comply with the doctors' requests. The seductive character restored their visibility and centrality by allowing them not merely to define themselves, but to save their lives from oblivion.

The cultural history of hysteria shows that one cannot know hysteria before photographing it. Meticulous visual observation was the origin of all Charcot's discoveries. An image will always say more than the best description. Charcot's use of photography aimed to translate and fix in an "alphabet of the visible" the "states of the body" (Didi-Huberman, 2020, pp. 54–55). Photography has an oracular power to reveal what Benjamin called the "optical unconscious," the unconscious that is revealed only through careful inspection of the image. The hysterical person's observable signs make her/his secret an almost visible pose. Nevertheless, this sign could only be photographed if the person posed, that is, if she remained motionless in front of the lens, sometimes for hours. This exaggerated the visibility of the hysterical signs. Charcot gave new life to hysteric women, but at the same time he relegated hysteria to the realm of fabrication, or as Didi-Huberman (2020) put it, the realm of lies. Photography was a "frenzied and almost ignoble" attempt (*ibidem*, p. 46), an exaggerated "extension of the evidence" (*ibidem*, p. 253), and thus a falsification (*ibidem*, p. 35). Through photography, and thus the visual cataloging of symptoms into "iconic narratives" or "pictures' devoid of context, the ideal of an absolute (clinical and not only) eye" was realized (*ibidem*, p. 59).

Beyond Charcot's intentions, the relevant aspect here is precisely this gallery or catwalk of pain and exhibition. In a kind of voyeuristic game, the most compliant of the models, she who would otherwise have been imprisoned in the pavilion of invisibility, where all gaze was denied, exaggerated her dance of pain according to the desire of the gaze of the doctors and other voyeurs. Being on the photographic set of the Salpêtrière allowed these women both to be visible and unforgettable in their exasperated poses - and to be somebody, as was the case with Mademoiselle Augustine, the star, the masterpiece of Charcot's theatre of hysteria.

To be(come) somebody, you need to be(come) visible. Visibility is the core of seduction. In order to seduce, one must be visible, or better, hyper-visible to capture and hold the gaze of the other. Charbonneau (2007) emphasizes the character of centrality, which could be considered a way of being visible here. The hysterical person always needs another, therefore, a gaze to show oneself to. The Other is pure gaze: he/she is a compliant witness to a hysterical person's performance. As Jaspers (1913) states, the hysterical world is characterized by "[...] desire to appear, both for oneself and for others [...]." The hysterical person is dependent on other people's meanings and values, or what (s)he considers to be such. Furthermore, the hysterical person is not satisfied with being seen but wants to be memorable or impressive. To achieve the goal of visibility, the hysterical person embodies a caricatured version of different human types, by exaggerating and intensifying them. (S)he is not actually a person but a figure (hence figurality) and gets trapped both in a universe of types to represent and through which to attract the others' gaze, and in postures and attitudes to impress others. This mode corresponds to what Charbonneau (2007) called typification, i.e., "embodying a totality in a figurative way."

Beyond gender: Degenderizing the hysteric world

Undressing the world of hysterical persons of sexuality and dressing it in seduction, on one hand, and visibility, on the other, leads us toward deconstructing hysteria as a gender pathology belonging to the feminine. The attempt to de-feminize hysteria is not new. The notion of male hysteria was initially connected to the post-traumatic disorder known as railway spine (Lerner, 2003); later, it became associated with war neurosis to prevent labeling soldiers with the "feminizing" label of hysteria (Showalter, 2020). Charcot himself seemed to have accepted the existence of male hysteria and distinguished it from female hysteria by linking it to traumatic shock rather than sexuality or emotional distress. Despite Charcot's attempt to recognize male hysteria, gender stereotypes were prevalent in his thinking (Lerner, 2003). Freud, in his analysis, argued that trauma was the cause of both male and female hysteria and that both had reason to exist.

Although in different ways, the hysterical way of being in the world concerns both women and men, as both are concerned with the issues of lack of being, seduction, and visibility. Certainly, seduction and visibility follow different trajectories in the female and male genders, but in both cases, the aim is the same: to engage the gaze of the other in order to overcome one's lack of being and thus define oneself. Relegating the others to spectators of the hysterical figurality does not allow for dialogue with them. Reciprocity is overwhelmed by visibility and "we-ness" by centrality.

The hysterical persons constantly live in the abolition of the private sphere. In other words, they live in a kind of overflow in the space in between oneself and others that is no longer inter-subjective but hyper-subjective, i.e., saturated with the subjectivity of the hysterical person and his/her centrality and figurality, relegating the other to the position of a mere spectator. The relational space, therefore, is a hypertrophically centralized space that is no longer a space to dialogue with the other, in which "I" and "Thou" can know and each other. Approaching the other would mean not only creating the basis for a relationship, but also decentralizing and renouncing emotional intensification, exchanging one's own desires with the other, and becoming intimate partners. From this angle, hysteria is a pathology of the inter-subjective space, in which there is a precipitous "reversal toward the center" (Charbonneau, 2007).

Conclusion: Lack of being, seduction, and visibility

As a way of being in the world, and not of being a woman, hysteria cannot in any way be polarized to the feminine world (see Esposito and Stanghellini, in press). If hysteria is not a gender pathology, then what is it a pathology of?

In this article we have discussed how at the core of the hysteric condition there is a lack of being, without explaining what we mean by this. This term is derived from Sartre, 1943 ontological analyses of the human condition. According to Sartre, the human condition is lacking because it is originally constituted as the fall of the Self from being in itself to being for itself, a form of consciousness that always feels separated from itself and contingent in its radical lack of foundation. In a nutshell, rather than feeling "at one" with oneself, coinciding with one's center, one feels like a spectator, looking at oneself from outside.

This essential feature of the human condition is epitomized in the psychopathological symptom called depersonalization, ie., a human being is an essentially and radically depersonalized form of being. A concise clinical vignette of a patient of one of us can help to summarize this phenomenon: "I feel distant from myself, as if I were not myself or in myself. As if I did not coincide with myself. I feel miserable because I cannot feel myself. I have not a basis on which I can build myself, my projects, my relationships."

From the angle of depersonalization, a lack of being can sometimes entail another psychopathological phenomenon called "autoscopy," seeing oneself from without. The narrative goes like this: "Sometimes, it is as if I were watching myself from without when I am doing something. Especially when I am deeply stressed, or perhaps when this happens as a consequence, I feel extremely stressed and anxious." Autoscopy is indeed a symptom listed for dissociative disorders, and a feature of hysteria. The patient's narrative continues: "Do not you see how mechanical, how unnatural, are my gestures? I feel like a mannequin. I realize how my movements are baroque, exaggerated, one pose after the other. As if I were cut in wood instead of being made of flesh." This feeling of inauthenticity and a kind of manneristic behavior are also symptoms of hysteria.

Lack of being is an unbearable feeling which urges a remedy, a distressing phenomenon that may kindle an attempt at self-healing or trigger a defense mechanism. From this angle, seduction can be seen as a means to compensate for the lack of being – one of many available, involuntary, and almost unconscious, compensating strategies to cope with lack of being, yet the one specific to the condition we call "hysteria." Minkowski (1927) developed the concept of "phenomenological compensation" and adopted it to present a dynamic view of the pathogenesis of schizophrenic symptomatology. This concept can be helpful to make sense of how persons with hysteria deal with lack of being. Seduction may be regarded as a secondary, reactive, or compensatory attempt to cover up for the primary lack of being. Persons diagnosed with hysteria try to compensate for their lack of being by seducing others, that is, capturing the attention of the other and using the other as a prosthesis in order to achieve a better "rooting" into themselves. The others' gaze is instrumental in reducing their uncanny feeling of lack of being.

Seduction, in its own turn, needs visibility. "I am afraid I became addicted to others, to being at the center of their attention. Not all others: those that are important to me. I always fall in love with those I call "the boss": the owner of the gym where I go for training, an older colleague, the doctor. Being at the center of their world gives me the feeling of being in touch with myself. However, it lasts very little time. Furthermore, in the end, I am back once more with this lack of myself."

How to become visible to others? One way is erotic seduction, *via*, for instance, the sexualization of relationships, as was the case during the long history of hysteria, culminating in Charcot's theatre with his hysterical vedettes. However, as we have seen throughout this article, there are several other ways to capture the other's gaze, including self-victimization, infantilism, intellect brightness, and hyper-generosity. These are all tactics to achieve recognition from the other. In this vein, as with the entire psychodynamic and phenomenological understanding of psychopathological signs and symptoms (Stanghellini and Mancini, 2017, 2018), these are, rather than ready-made outputs of a deranged brain or mind, the self-healing attempts of a person struggling against an intolerable and uncanny experience like lack of being.

In this context, the clinical complexity of hysterical signs and symptoms can be grasped and deciphered as inscribed in the patients' life-world and in her/his life history. This is a specific kind of psychopathological condition in which a lack of coenaesthetic contact with oneself is compensated by seducing the other, gaining some sort of visibility by impressing them with theatrical, dramatic, or intensified poses (Stanghellini, 2019; Stanghellini et al., 2019; Mancini and Esposito, 2021).

Understanding hysteria as an anthropological unit, beyond the feminine and the masculine, is the route to accessing meaning and bringing down the last bastion: that hysteria is female.

To avoid generalizations and misunderstandings, we would like to add the following remarks before concluding our article. First, seduction – on which we focused in this article – is not the only way persons with hysteria try to compensate for their lack of being. Other strategies include defense mechanisms such as repression, conversion, regression, and acting out. Second, seduction is a compensation strategy we find at work in other conditions including, for instance, narcissistic personality, although with relevant differences that we will explain shortly. We want to highlight the centrality of seduction and its typical characteristic in the world of the hysteric person. Last but not least, a lack of being, for which seduction is possibly compensating, is not specific to hysteria. As is well known, a characteristic experience of narcissistic people is a kind of lack of being that consists of a feeling of inner emptiness that requires a recurrent infusion of external confirmations about one's own importance and value. The difference between hysteria and narcissism, we suggest, is the different ways of coping with a lack of being. Whereas persons with hysteria compensate *via* seduction and centrality to keep the other available and obtain recognition, narcissistic persons strive to attain wealth, beauty, power, and fame to compensate for their lack of being. The imperatives of narcissistic persons, in our age, are production, utility, and optimization (Stanghellini, 2022). Being is equivalent to producing by adapting to existence and by optimizing it. "Utility" means that every action must be directed toward a purpose and, therefore, primarily to production. "Optimization" means that anything that costs more than it produces is a dead branch to be cut. Every aspect of the narcissistic person's existence is managed as a performance, the aim of which is to compensate for one's feeling of insufficiency and inferiority, live up to others, and surpass them.

This strategy to get recognition, and the personal values on which it is based, is radically different from the one adopted by persons with hysteria, ie., seduction to keep the other available in an attempt to compensate for lack of being. We explored the implications of this lack of being in the world of persons with hysteria. Its origins lay beyond the scope of the article.

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

MM wrote the first draft and each section of the manuscript, contributed to the final writing and revision of the manuscript, and read and approved the submitted version. GS contributed to the final writing and revision of the manuscript, and read and approved the submitted version. MS, SM, and VU contributed to the bibliographic research and literature review, and approved the submitted version. 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.

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*CORRESPONDENCE
Leonor Irarrázaval
lirarrazaval@udla.cl

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Phenomenological considerations on empathy and emotions in psychotherapy

Leonor Irarrázaval[1,2]* and Juan Pablo Kalawski[3]

[1]Facultad de Salud y Ciencias Sociales, Escuela de Psicología, Universidad de Las Américas, Viña del Mar, Chile, [2]Unidad de Filosofía, Departamento de Psiquiatría y Salud Mental, Hospital Clínico, Universidad de Chile, Santiago, Chile, [3]Facultad de Ciencias Sociales y Humanidades, Grupo de Investigación en Psicología Clínica y Psicoterapia, Carrera de Psicología, Universidad Autónoma de Chile, Temuco, Chile

In this article we will present a phenomenological approach to empathy and its relationship with emotions in the context of psychotherapy, highlighting the importance of empathy as a key element of the therapist-client relationship and therapeutic process, regardless of the therapist's approach. We will use a consensus definition of empathy taken from phenomenologically oriented philosophy to analyze therapist's empathy, as well as client's self-empathy and client's empathic communication with others. We will discuss emotions as they usually manifest in the context of psychotherapy, specifically describing how certain emotions can disturb empathic communication in close personal relationships and how it is possible to reestablish empathic communication in psychotherapy. This article it is not only based on evidence from scientific literature but also incorporates the authors' practical knowledge of psychotherapy.

KEYWORDS

empathy, therapist's empathy, client's self-empathy, emotion schemes, existential meanings

Introduction

There are number of clinical studies and empirical findings that place empathy at the heart of psychotherapy. One of the first authors to highlight the crucial importance of empathy as a common factor of change in psychotherapy was Rogers (1957, 1963). Rogers suggested that when the therapist's communicative style shows understanding and acceptance of the clients' subjective experiences, this facilitates the client's awareness and acceptance of their emotions. As a result, this process act as an antidote to the client's feelings of worthlessness and helps them value their own subjective experience as a guide for their behavior. Rogers put empathy at the center of his approach, to the extent that he considered it one of the necessary and sufficient conditions for therapeutic change. Outside of the client-centered tradition, empathy has also been recognized as a crucial element in psychotherapy, for example in Kohut's (1977) psychoanalytic work. Empirical findings have suggested that therapists' empathic responses toward clients' subjective experiences help them to increase their awareness of emotions, recognize their needs, and develop more effective affect regulation strategies (Watson et al., 1998; Paivio and Laurent, 2001; Watson, 2002). Additionally, it has been suggested that therapist's empathy helps clients develop positive self-treatment by accepting their subjective experiences as well as helps them feel more secure in close interpersonal relationships. Therapist's empathy also helps clients overcome negative self-treatment, such as silencing, neglecting, oppressing, and controlling their subjective experiences, which can contribute to several interpersonal difficulties (Watson et al., 2014). Moreover, Barrett-Lennard (1997) argued that therapists' empathy facilitates the development of self-empathy in clients, and that, as they become more empathic toward themselves, they become more open and empathic toward others.

Empathy has also been a central theme of philosophical analysis in the tradition of phenomenology. Since the end of the 19th century, when Vischer (1872) introduced the German term *Einfühlung* (from the Greek term empatheia: em "in" + pathos "feeling"), philosophical debates regarding its definition also began (Geiger, 1910). *Einfühlung* was translated into English by Titchener (1909) as "empathy" and introduced by Lipps (1907) into the field of the humanities and social sciences. The conceptual debate about empathy has continued until today involving other disciplines, such as cognitive sciences and psychology (Moran, 2004; Zahavi, 2022). This divergence regarding the definitions of empathy is problematic for empirical research as well as for training and intervention in psychotherapy. Therefore, we will use a consensual definition of empathy derived from phenomenologically oriented philosophy. Phenomenologists recognize that empathy allows access to the subjective experience of other people (including emotions) with the awareness of the other as "an-other" (Husserl, 1959; Stein, 1989).

Like empathy, emotions are also crucial to psychotherapy. Phenomenologists also agree that any form of conscious experience has a core affective dimension, even the simplest perceptual experience (Szanto and Landweer, 2020). Although emotions have always been present, academic focus on emotions as such is more recent than the focus on empathy. Early conceptualizations of psychotherapy viewed emotions as caused by unconscious drives. Thus, therapists were encouraged to work with these unconscious drives rather than with emotions *per se*. Currently, the dominant cognitive approach also views emotions as a byproduct, this time of thoughts. So, therapists are encouraged to work with thoughts, which is presumed to in turn change emotions. Even though this is still the mainstream view, in recent years there has been a movement toward recognizing that emotions are not just byproducts, but important processes crucial to change in psychotherapy (Lane et al., 2015). We will follow phenomenologists and psychotherapists who view emotion and cognition as forming integrated wholes (Colombetti, 2007; Greenberg and Goldman, 2019).

The emphasis on both empathy and emotions is clear in Emotion-Focused Therapy (Greenberg and Goldman, 2019), from which we will use the concept of "emotion schemes," which are activated in the context of close personal relationships, such as couples, friends, families, and colleagues. We would like to highlight that these emotion schemes relate to "existential meanings" (Irarrázaval, 2022). Existential meanings are not related to problems of reason, that is, to metaphysical or philosophical questions, such as the question of freedom or the meaning of life. Existential meanings are related to a basic sense of oneself emerging in the interaction with other people that predispose us to communicate in a certain way toward ourselves, others, and the world. We will focus on disturbing emotion schemes, namely "primary maladaptive emotion schemes" (Greenberg and Goldman, 2019) or "core pain" (Timulak and Pascual-Leone, 2015) to describe how these emotion schemes can disturb empathic communication, as well as how to re-establish empathic communication in psychotherapy. This article it is not only based on evidence from scientific literature but also incorporates the authors' practical knowledge of psychotherapy.

Basic and extended empathy applied to psychotherapy

Within the tradition of European phenomenology there is agreement that, in its minimal definition, empathy is a mode of intentionality that makes it possible to access the subjective experience of another person, with the awareness of the other's experience as being different from one's own (Husserl, 1959; Stein, 1989). This minimal definition of empathy not only highlights the distinction between one's own experience and that of an-other, but also focuses on the "foreign" experience of the other person, thus making it already possible to distinguish between empathy and a feeling of oneness. For instance, Allen's (1976) reading of Husserl's "*Das Kind. Die Erste Einfühlung*" presents the developmental process through which the "first act of empathy" enables the child to recognize the other as an-other, with a life of their own and to view the surrounding world as an intersubjectively formed lifeworld. At an early stage of development, there is an instinctive relatedness between the child and their caregiver, which is based primarily on the child's desire to have their needs fulfilled, so empathy – an intersubjective relatedness between two different individuals – is not yet developed. In the process of awakening to the surrounding world, empathy enables the child to recognize their caregiver as an individual with their own needs, which are different from the child's. From this approach, empathy enables the distinction between one's individual experience and that of another individual's, so it is constitutive of intersubjectivity.

There is also agreement regarding a distinction between two forms of empathy: basic and extended empathy. Jaspers (1959) states that there are two different modes of understanding psychic phenomena, whose subjectively experienced character cannot be quantified or objectified in terms of scientific knowledge: the "static" and the "genetic" modes. The static mode involves the understanding of psychic states through the other person's manifestations directly presented to us, including body movements, gestures, and facial expressions, as well as personal materials such as works of art and writings (objective psychopathology). Yet, it is important to bear in mind that this static mode of understanding is not a psychological understanding as such. Psychic or mental phenomena that are not directly present can only be psychologically understood by means of the genetic or empathic mode, making connections as to how one mental phenomenon emerges from another (subjective psychopathology). Accordingly, Jaspers' static mode of understanding corresponds to a basic form of empathy, while his genetic or proper psychological mode of understanding corresponds to an extended form of empathy. Basic empathy enables direct access to the experience of others *via* perception of their non-verbal bodily expressions. Basic empathy is crucial in the mother-infant relationship, as the infant cannot communicate verbally (Winnicott, 1965). Basic empathy corresponds to what Gendlin (2012) called "the body's relational knowing." However, the experience of other persons includes a sense of themselves, others, and the world, which is not directly present in primary appearances of non-verbal bodily expressions. This is the starting point for extended empathic or psychological understanding (Irarrázaval, 2020). Extended empathy transcends apparently perceived phenomena, being basic empathy its condition of possibility. In other words, empathy can be extended to understand another person's subjective experience from a psychological viewpoint (Jaspers, 1912, 1959), beyond one's capacity to perceive their non-verbal bodily expressions.

From a phenomenological approach, both basic and extended empathy toward other people must preserve an awareness of the distinction between the experience of the empathizer and the experience of the empathized. Consequently, when referring to empathic or psychological understanding, we want to make a conceptual clarification with respect to other possible definitions of extended empathy. We are not conceptualizing empathic or psychological understanding as perspective-taking or cognitive empathy in the sense of an imaginative speculation of how one might feel if one were in another person's situation ("putting oneself in the other person's shoes") or in terms of Fuchs (2017a) as an "explicit imaginary transposition into the other's situation" (p. 43). In contrast, we conceptualize empathic or psychological understanding as a multilevel exploration of the unique experience of an-other, where this experience is different from one's own. Ultimately, this psychological exploration is aimed at knowing the other person's worldview, including not only affective-existential and cognitive aspects, but also cultural, social, and historical ones (Irarrázaval, 2020).

We do not want to suggest that theoretical inferences or imaginary simulations are not strategies that in some way can facilitate the empathic or psychological understanding of another person, but rather we want to point out that these strategies are not themselves empathy. In line with a precise phenomenological definition of empathy, the experience to be empathized with is not the experience of the empathizer, but the "foreign" experience of another person, namely the empathized (Zahavi, 2014a,b, 2015). Differently put, theoretical inferences or imaginary simulations focus on the experience of the empathizer who unilaterally uses their own experience to try to understand the experience of another person. Unilateral or "solipsistic anticipations" of other persons, such as interpretations, inferences, prejudices, and the like, imply that we somehow impute or project our own thoughts and imaginations onto the other person's experience, without necessarily preserving the distinction between the experience of the empathizer and the experience of the empathized (Irarrázaval, 2020). The danger of losing this distinction is that the other person's experience could be reduced to the experience of the one trying to understand it, eventually moving away from how the other person actually makes sense of their experience. This communicational mismatch can lead not only to confusion in the interaction with other people but even to psychopathology, for example, in extreme cases of paranoia in which the person attributes to other people intentions of persecution, harm and potential homicide, which are related to the condition of the person's "ontological vulnerability" and not with the true intentions of others (Irarrázaval, 2022).

According to Zahavi (2016), empathic communication requires a form of second-person engagement between the empathizer and the empathized, namely a "second-person address." This second-person engagement between "I" and "Thou" constitutes a new "we-identity" with a shared "communicational" project ("we-triadic structure"), which has the potential to transform our self-knowledge. On the one hand, the empathizer recognizes the experience of the empathized and, on the other hand, the empathized recognizes that their experience is being empathized with. When this psychological understanding is fully empathic, the person recognizes themselves as empathized with, which has been acknowledged as an important factor for change in psychotherapy (Rogers, 1957; Elliott et al., 2011; Watson et al., 2014). However, the communication between therapist and client differs from other types of close personal relationships, such as couples, friends, families, and colleagues, mainly because the conversation in psychotherapy focuses on the exploration of the client's experience and not the therapist's. The psychological understanding that guides the therapist is not motivated by mere curiosity or the spontaneity of an ordinary conversation of everyday life. Therapy does not consist of an exchange of experiences as occurs between members of close personal relationships, in the sense that space is usually given more or less equally for each to share their own experience. In psychotherapy it is only the client who shares their experience; the therapist can do it sometimes, but it is not the rule. In this way, the therapist is unilaterally oriented to psychologically understand the client's experience through extended empathy, while the client is oriented, not to understand the therapist, but to understand themselves through self-empathy. In other words, there are "normative limits of mutuality" in the therapist-client relationship, in the sense that the therapist attempts to act on the client to psychologically understand their experience, which depends on a mutuality that is never to be complete (Buber, 1970).

Ratcliffe (2017) conceives therapist's empathy as an extended exploratory process through which the client's experience is progressively revealed to the therapist. How is the client's experience revealed to the therapist? Hutto and Jurgens (2018) suggest that therapist's empathy is extended in the sense that, interacting with the client, one is obviously moved by perceiving their bodily expressions and, most importantly, understands their situation by their stories. In this latter sense, therapist's psychological or empathic understanding is conceived as a properly discursive and, especially, narrative-driven form of engagement with the client. Precisely because the therapist is oriented toward psychological or empathic understanding of the client and not *vice-versa*, the therapist's interventions must be in accordance with the client's experience, not what the therapist thinks that experience is, nor the therapist's experience about the client's experience. Although the experience of the clinician in interaction with the client has been pointed out in its possible contribution to the psychiatric diagnosis, for example in schizophrenia (Rümke, 1990), in psychotherapy the therapist's awareness of their own experience emerging in the interaction with the client serves to preserve the required distinction between them, so that the therapist's intervention responds to the actual experience of the client that is being revealed in the therapeutic process. Thus, the therapist does not unilaterally attribute mental states to the client, such as beliefs, intentions, meanings, and emotions, nor does the therapist focus on imaginatively simulating how they would feel in the client's situation. The therapist is also not a passive observer but is in a face to face "second-person relationship" (León et al., 2022), oriented to psychologically or empathically understanding the client through their displaying or revealing their subjective experience. This implies that the depth of the therapist's empathy will relate to the depth of the client's communication (Gendlin, 1986).

When the client feels understood, that is, feels empathized with by the therapist, a full empathic communication is achieved, facilitating change in the psychotherapeutic process. Additionally, as the therapist psychologically or empathically understands the client's experience, the client empathically understands their own experience through self-empathy. Making a person's own experience the focus of their empathic self-understanding is indeed the focus of psychotherapy. On many occasions, people do not understand their own experience. For example, they experience emotions that they consider inappropriate to a situation, or they act in ways that are incomprehensible to themselves because they are dissociated or disconnected from their own subjective experience. Of course, self-empathy does not require preserving the distinction between the experience of the empathizer and the experience of the empathized, since in this case empathizer and empathized are the same person. What this case requires is the distinction between pre-reflective and reflective levels of self-awareness which are processes of selfhood of the first-person perspective (Zahavi, 2020). So, in self-empathy, the distinction between pre-reflective and reflective self-awareness takes the place of the distinction between first- and second-person perspectives in empathy between different people, for instance, therapist and client. This relationship between pre-reflective and reflective levels of self-awareness from the first-person perspective is crucial to make explicit in psychotherapy for all kinds of concerns, from mild relationship conflicts or vocational issues to severe difficulties such as paranoid thoughts or hallucinations. In psychotherapy, the relationship between pre-reflective and reflective levels of self-awareness is addressed through self-empathy, which is an explicit psychological understanding of the client's first-person experience facilitated by the therapist's extended empathy. In other words, self-empathy involves the application of reflective awareness to the client's own pre-reflective experience. Self-empathy is thus an extended, narrative form of empathy. The importance of applying reflective awareness to one's own experience is widely regarded as crucial to mental health, from psychoanalysis's dictum of making the unconscious conscious, to the Rogerian view of congruence between experience and self-concept, to the cognitive-behavioral task of becoming aware of one's own cognitive distortions. Some readers may thus wonder whether self-empathy is tantamount to insight. As with the word "empathy," the word "insight" can mean different things. In the psychotherapy context, the term often refers to an event in which the person makes new connections (Hill et al., 2007). Under this meaning of the word, insight is a product of self-empathy. We would like to highlight that self-empathy is a process rather than a state or an outcome.

Emotion schemes and maladaptive emotion schemes or core pain

One of the tensions in the conceptualization of emotions relates to which aspect of emotions is emphasized. On the one hand, emotions are internally felt. On the other, emotions are intentional, that is, about the world. We believe that Müller's (2022) proposal is a promising way to integrate these two aspects into a coherent phenomenology of emotions. He argues that the way one feels in having an emotion is not a perception-like awareness of "evaluative properties" of its object, but instead constitutes the taking of a stand or position about this object considering its evaluative properties. Many therapists teach their clients that they can change their feelings by changing their thoughts. To some extent, this is true, but it is also true that, many times, changes in thoughts do not lead to changes in emotions. In addition, Colombetti (2007) has argued that it is phenomenologically implausible for cognitive appraisals to precede emotions. She proposed that appraisal is fully integrated into emotional experiences. Emotions, thoughts, action, and interaction form integrated wholes. In the psychotherapy literature, Greenberg and his colleagues (Greenberg et al., 1993; Greenberg and Paivio, 1997; Elliott et al., 2004; Greenberg and Goldman, 2019) have proposed the concept of "emotion scheme" to refer to these integrated wholes. The word "emotion" in emotion scheme highlights that emotions play a central role in these multicomponent organizations. Emotion schemes are learned through experience and produce complex, idiosyncratic emotional experiences when they become activated. Emotion schemes include five elements. The central, organizing element in an emotion scheme is the emotion itself, such as anger, fear, or tenderness. The perceptual element is composed of the cues that activate the emotion. For example, a client recalled the way everybody looked at his mother when she was drunk at a party. Emotion schemes also have a bodily element, including such experiences as clenched jaws, fast breathing, etc. The fourth element are existential meanings, that is, what it means for oneself to exist in the world when the emotion scheme is active. These meanings are based on the emotion but also include idiosyncratic elements. For example, fear is associated with danger, but a person may symbolize a specific experience as "I felt like the Little Red Riding Hood walking alone in the forest." The fifth element of emotion schemes is the motivational element. This latter element includes action tendencies, such as wanting to hide or wanting to punch somebody. The motivational element also includes a deeper aspect: existential needs, such as the need for validation and the need for support.

Emotion schemes are not exclusive to psychopathology. Rather, they are a general concept to explain psychological functioning. Additionally, emotion schemes not only include emotions in a narrow sense of just labels such as "angry" or "sad." Emotions are more than mere labels for subjective feelings. They always imply a positioning in the world (Müller, 2022). To describe difficulties with empathy in mental health concerns, we focus on disturbing emotion schemes, namely "primary maladaptive emotion schemes" (Greenberg and Goldman, 2019) or "core pain" (Timulak and Pascual-Leone, 2015). Greenberg and Goldman (2019) explain the concept thusly:

> Primary maladaptive emotions are core painful emotions that are more a response to past unresolved issues and unmet needs (based often on traumatic learning) than an adaptive response to current circumstances. Consequently, they do not prepare the individual for adaptive action in the world. Maladaptive primary feelings are responses that may once have served a useful purpose, but when presently activated in current situations they lead to responses that are now inappropriate (e.g., fear in response to affection from a past abuser is now activated in response to a loving other or feeling the shame of inadequacy when one is criticized, which stems from invalidation by one's peers or parents). As such, they do not provide useful information to guide present action for the adult. Because maladaptive primary emotions do not change with changing circumstances, they often leave the individual experiencing them feeling stuck, hopeless, and helpless (i.e., depressed or anxious). Present functioning is ruled by the past, and the newness and richness of the present moment is lost (p. 65).

As is implied by the above definition, primary maladaptive emotion schemes can blind the person, rendering them unable to visualize the other's experience, as the current interaction is filtered through the lens of past painful experiences. Specifically, then, we propose that primary maladaptive emotion schemes disrupt basic empathy. Therefore, these schemes not only lead to unpleasant emotions; they also lead to the interpersonal difficulties integral to mental health concerns. These interpersonal difficulties, in turn, lead to more psychological pain. We should clarify that we are not claiming that maladaptive emotion schemes are the only possible disruptor of basic empathy. For example, Robinson et al. (2021) suggested that difficulty with basic empathy can be due to a mismatch between neurotypical and neurodivergent forms of intersubjectivity. Nevertheless, we suggest that primary maladaptive emotion schemes are a common impeder of basic empathy. Timulak and Pascual-Leone (2015) articulated that these maladaptive, core emotions can be clustered as sadness-related, shame-related, and fear-related. Let us briefly review each of them:

- Shame: Shame is basically an adaptive emotion, as it alerts the person that their social standing is in peril (Sznycer et al., 2018). This emotion thus motivates one to change one's behavior to restore harmonious social relations. There is, however, a difference between shame as a response to a specific situation and internalized shame as a core sense of oneself. This primary maladaptive shame involves a sense of worthlessness of the whole person. This shame often comes from a history of humiliation and is part of a core sense of self. For people with primary maladaptive shame, any self-expression is automatically accompanied by a feeling of shame (Greenberg and Paivio, 1997). Maladaptive shame thus inhibits authenticity and disrupts interpersonal flow. The person is not attuned to the actual interaction but instead assumes that the other holds a negative view toward themselves. From the perspective of the other, the behavior of the person with maladaptive shame is not transparent, as it cannot be understood based on the ongoing interaction.
- Sadness: This emotion is associated with isolation and loss of connection with other people. It points to the existential need for closeness and love – more specifically, being able to count on someone for comfort, protection, support, and, generally, help. This is a healthy need and sadness is basically a healthy emotion. When a child is emotionally neglected, they build a maladaptive sadness scheme, characterized by a tendency to view situations as abandonment. For example, a friend being late to lunch might be taken personally and become emotionally hurtful. The primary emotional response in these situations is sadness, but the person will often defend against this experience and either lash out at the friend or adopt a posture of resignation. As with the case of maladaptive shame, maladaptive sadness clouds interpersonal attunement. In the case of the friend being late, there are multiple possible reasons for this, and a healthy response would involve being open to contextual information. But the person with a maladaptive sadness scheme will instead make an

abandonment interpretation that may not be consistent with the situation. This impedes an empathic attunement to the friend's experience.

- Fear: This is a crucial emotion that mobilizes organisms to escape from danger. From an evolutionary standpoint, mistaking a dangerous situation as safe is deadly. However, mistaking a safe situation as dangerous may be costly, but preferable to the alternative. Thus, it makes sense that people respond with fear when faced with ambiguous situations. This natural tendency is even more pronounced when people have experienced significant trauma during childhood. A maladaptive fear scheme then leaves people vulnerable to experiences of terror and dissociation in response to situations in which there is a potential for loss of control (Timulak and Keogh, 2020). It is important here to emphasize that primary maladaptive fear is different from the more common kind of anxiety that is produced by thoughts. For example, thinking about doing poorly on a job interview can generate anxiety. By contrast, primary maladaptive fear is automatic and pre-reflective. When the person is in the throes of terror, attention becomes narrowly focused on escaping the situation, impeding the "decentering" necessary for empathy (Fuchs, 2017b).

Empathy and mental health problems

Empathy issues have already been noted in dark personality traits, as well as in autism spectrum disorders, for example (Irarrázaval, 2020). Here, however, we suggest that empathy issues are common in a wide range of mental health concerns. Rather than addressing specific mental health concerns, we will discuss in general terms their relationship with empathy. First, we first need to briefly explain the two main sources of mental health concerns proposed by Greenberg et al. (1993). According to these authors, psychological dysfunction stems from: (1) the ongoing conscious construction of meaning and (2) the automatic activation of painful pre-reflective experience. Conscious meaning is the application of socially constructed symbols to make sense of one's experience. As humanistic authors (Rogers, 1961; DeRobertis, 2006) have pointed out, these constructions can conflict with organismic (pre-reflective) experience, as in the statement "boys do not cry." Someone who says this to a child is most likely not being empathic. Not receiving proper empathic or psychological understanding then affects self-empathy, as in coming to believe that boys do not cry and trying to apply that generalization to one's own experience. To illustrate the second source of dysfunction, let us take the example of a person who is very sensitive to abandonment. Being very sensitive to abandonment involves the automatic activation of painful experience. This experience is pre-symbolic, embodied, and not representational (Gendlin, 1982). In addition to agreeing with Greenberg et al. (1993) that pre-reflective experience can itself lead to mental health concerns, we note that this experience is not only subjective but also intersubjective and thus tied to difficulties with empathy toward others. This is clear, for example, in the sensitivity to abandonment, an inherently intersubjective experience.

Clinical experience shows that mental health concerns always feature interpersonal difficulties. In fact, complaints such as "I am depressed" or "*estoy enferma de los nervios*" may be an artifact of the ubiquity of cultural messages that encourage the internalizing of problems. In addition, the exploration of symptoms quickly runs out. By contrast, exploration of interpersonal concerns is richer and feels alive. Some clients skip the symptom talk altogether and simply complain of interpersonal difficulties in the context of close personal relationships, such as couples, friends, families, and colleagues. Such clients often meet the requirements for psychiatric diagnoses, but the symptoms are not what motivate them to seek help. In the present article, we do not pursue to explore the specific mechanisms that may lead to specific kinds of interpersonal difficulties. Rather, we would like to take a general look at interpersonal difficulties considering our previous discussion of empathy. As we saw, it is useful to distinguish between basic and extended empathy. We would like to propose that the interpersonal difficulties present in mental health concerns involve difficulties with basic empathy. That is, what is disturbed is the spontaneous intersubjective flow necessary for social functioning.

Emotion schemes that interfere with basic empathy are those in which a self-disturbing experience of a previous life situation is pre-reflexively reactivated. These emotion schemes can disturb an empathic response. This means that, in certain situations, a person's emotional reaction is tied to a previous disturbing experience and does not correspond to the subjectivity of another person in the present. For example, a depressed person may incorrectly assume that others do not like them, or a person with post-traumatic difficulties may interpret benign behaviors from others as rejecting. It is worth pointing out that the disturbing emotion schemes are unique and personal in terms of existential meanings, so certain situations that could be seen as obviously disturbing or even traumatic do not necessarily entail disturbing or traumatic consequences in the person who experienced them. Conversely, certain situations that could be seen as obviously not disturbing or even trivial, can have disturbing or traumatic implications. For example, a person who suffered bullying in childhood, when exposed to a harmless joke might not have an emotional reaction of humor, but of shame or anger, being unable to take the joke as such, but consider it offensive due to previous disturbing or traumatic experiences. However, this empathic disturbance would not occur in other situations of everyday life that are not related to the previous disturbing or traumatic situation, which the same person could respond empathetically to.

Using extended empathy to reestablish basic empathy

In psychotherapy, psychological or empathic understanding is acquired through the unfolding of disturbing emotion schemes involved in the client's subjective experience. This unfolding includes emotional expression on the part of the client. Additionally, the client discloses the existential meanings that challenged their vulnerabilities in the context of a close personal relationship. The therapist promotes self-empathy in the client, with the corresponding distinction between aspects of their emotional schemes that relate to original disturbing or traumatic experiences. In this manner, the client begins to distinguish between those emotional reactions that have to do with a past life situation from those emotional reactions that correspond to the present life situation. Thus, interaction with the therapist enables the client to reestablish empathic communication through dialog, overcoming the client's solipsism. Here, solipsism refers to a "self-centered" state (Irarrázaval, 2018) in which the other person's point of view is reduced to one's own. In other words, blinded by their own emotional disturbances, the person cannot see the other as an-other, independently from their own emotional experience. In such solipsistic state, a person projects their own experience onto the other's experience, manifesting an empathic failure.

For example, a client who experienced sadness without knowing its true origin, initially attributed it to an increased work stress because of the pandemic. In this situation there was a difficulty with self-empathy. In psychotherapy, the therapist's extended empathy and the client's self-empathy allowed for the exploration of the experience of sadness and its existential meaning. In this way, the client understood the existential meaning of abandonment connected to the recent loss of a loved one, a grief that had been blocked. The emotional expression of sadness and its corresponding association with the loss situation resulted in symptomatic relief and disclosure of the existential need for closeness, which moved the client from isolation to actively seeking social contact. In another scenario, a woman may communicate in an aggressive, demanding or dominating way with her husband, impeding empathic communication between the two. Aggressive, demanding, or dominating interactions are different from assertively expressing one's needs. In the latter case, the person is aware that their needs are their own, thus preserving the self-other distinction necessary for empathy. If the woman is aggressive, demanding, or dominating with her husband, she addresses him as the target of her anger without visualizing his subjectivity. Also, in a close personal relationship, assertive communication usually occurs automatically as part of the interactional flow. Thus, aggressive, demanding, or dominating interactions in close personal relationships usually involve difficulties with basic empathy. In this case, the therapist deploys extended empathy to unfold the woman's experience. It may then become clear to both the therapist and the woman that anger is not her primary feeling. Rather, there is a core feeling of loneliness and sadness. This sadness, once fully experienced, points to the need for support. By recognizing this need, the woman has moved from seeing her husband as a target of anger to seeing him as a potential source of support. This allows her to be more open to visualizing his subjectivity. Next, the woman can express to her partner her need for support in a non-blaming manner. This move makes the woman more transparent to her husband, which makes it easier for him to empathize with her and allows him to respond compassionately, meeting her need for support. Over time, as partners respond positively to each other's existential needs, each partner's disturbing emotion schemes transform, which helps restore basic empathy to the relationship. Additionally, Kalawski (1997) reported another interesting example of the relationship between emotions and empathy. A client expressed resentment toward her partner. The therapist then guided her through an exercise consisting of adopting the breathing, posture and facial expression of a person experiencing tenderness. After this exercise, the client said she spontaneously shifted her view of the situation and was able to consider her partner's experience. The client shifted her literal and her emotional positioning (Müller, 2022), facilitating basic empathy. Recent studies have also shown that the emotion of tenderness facilitates the process of couple therapy (Veach, 2016; McNally, 2020). We believe that tenderness as an emotion may be at the core of empathy and suspect that maladaptive emotions and tenderness mutually inhibit each other. Thus, at times, working directly with tenderness can help improve basic empathy, while at other times it may be more helpful to directly address whatever maladaptive emotions may be present.

Conclusion

In this article, we have addressed the relationship between empathy and emotions, with an application to psychotherapy. We have employed a basic as well as an extended notion of empathy as defined in the philosophical phenomenological tradition. We have also included the notion of self-empathy. We have proposed that an extended form of empathy is the one employed by the therapist and that self-empathy is the form developed by the client in psychotherapy. Regarding emotions, we have employed the notion of emotion schemes, and proposed that maladaptive or disturbing emotion schemes impede basic empathy. We have argued that certain life situations negatively affect people's basic empathy through maladaptive emotion schemes and that the therapist's extended empathy can reestablish it. In this sense, therapist's extended empathy can be conceived of as an external event that facilitates processes of change in psychotherapy. We have also suggested that therapist's extended empathy develops client's self-empathy in psychotherapy. Self-empathy improves client's narrative coherence. Studies have shown that this improved narrative understanding of disturbing emotion schemes is associated with psychotherapy outcome (e.g., Krause, 2005; Basto et al., 2021). This self-understanding in turn leads to a reestablishment of client's basic empathy and facilitates their extended empathy toward other persons, preserving the distinction between client's and others' experiences. We believe that our conceptualizations of basic and extended empathy and understanding of their relationship with emotions may shed light on the common factors of the therapeutic process by specifying the ways in which therapist's extended empathy and client's self-empathy are put into play. This has significant implications for future empirical uptake of the notion of empathy within phenomenological research, as well as for use in education and to advance psychological interventions beyond a specific psychological theory or model.

Data availability statement

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

Author contributions

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

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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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EDITED BY
Elizabeth Pienkos,
Clarkson University, United States

REVIEWED BY
Ryan David Kemp,
Central & North West London NHS Foundation Trust; Brunel University, United Kingdom

*CORRESPONDENCE
Anthony Vincent Fernandez
afernandez@health.sdu.dk

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Recontextualizing the subject of phenomenological psychopathology: Establishing a new paradigm case

Guilherme Messas[1,2] and Anthony Vincent Fernandez[3,4]*

[1]Santa Casa de São Paulo School of Medical Sciences, São Paulo, Brazil, [2]Collaborating Centre for Values-Based Practice in Health and Social Care, St. Catherine's College, University of Oxford, Oxford, United Kingdom, [3]Department of Sports Science and Clinical Biomechanics, University of Southern Denmark, Odense, Denmark, [4]Danish Institute for Advanced Study, University of Southern Denmark, Odense, Denmark

Recently, there have been calls to develop a more contextual approach to phenomenological psychopathology—an approach that attends to the socio-cultural as well as personal and biographical factors that shape experiences of mental illness. In this Perspective article, we argue that to develop this contextual approach, phenomenological psychopathology should adopt a new paradigm case. For decades, schizophrenia has served as the paradigmatic example of a condition that can be better understood through phenomenological investigation. And recent calls for a contextual approach continue to use schizophrenia as their primary example. We argue, in contrast, that substance misuse provides a better paradigm case around which to develop a contextually sensitive phenomenological psychopathology. After providing a brief vignette and analysis of a case of substance misuse, we explain why this kind of condition requires considerable sensitivity and attention to context, better motivating the incorporation and development of new contextually sensitive approaches.

KEYWORDS

phenomenological psychopathology, phenomenological psychiatry, substance use disorder, phenomenology, situatedness, context

Introduction

Phenomenologists, like most philosophers, are often accused of being too abstract. When articulating fundamental structures of subjectivity and the lived world, they often lose sight of how experience can also be shaped by one's socio-cultural context. For a philosopher concerned with experience in general, the acontextual nature of their investigation may be a feature—not a flaw—of their approach. However, the accusation of abstraction becomes more compelling when we turn to fields of applied phenomenology, which often aim to understand the experiences of particular subjects, rather than experience in general.

This is certainly the case for the field of phenomenological psychopathology, which aims to understand and describe experiential alterations that occur in mental illness.

When describing the experiences of people living with schizophrenia, for instance, one makes claims about a particular population, rather than about experience in general. However, contemporary phenomenological psychopathologists often develop their accounts without much sensitivity to the socio-cultural context of the people they study. In most cases, phenomenological psychopathologists take themselves to be investigating alterations in fundamental structures of experience. Research on schizophrenia, for instance, has focused on the disturbances of minimal selfhood, or the basic sense of "for-me-ness" that is said to accompany all experience (1, 2). And research on melancholic depression has focused on disturbances of implicit temporality, such as diminishment of the conative drive, or the implicit urge or striving toward the future (3). There seems to be a general assumption that these structural alterations are not shaped by cultural, linguistic, or religious background, life circumstances, and so on. This still leaves room for various contextual factors to fill in the *content* of experience—for instance, the content of delusions or hallucinations among people with schizophrenia can vary from culture to culture. But the primary focus of phenomenological inquiry has typically been on more fundamental structural alterations, which are presumed to be untouched by cultural differences.

However, we do find some contextually sensitive approaches in both classical and contemporary phenomenological psychopathology [e.g., (4, 5)]. Recently, Elizabeth Pienkos outlined some of these approaches and argued that the field of phenomenological psychopathology as a whole should incorporate more sensitivity to context. She shows how classical phenomenological psychopathologists attended both to the particularities of individual patients, such as their psychological style or life history, as well as aspects of their lived world, such as social stressors, cultural values, and relations with others (6). Some contemporary approaches also incorporate more sensitivity to situation and context by drawing on insights from other approaches in philosophy and the sciences, such as the bio-psycho-social model (7), hermeneutics (8), or enactivism (9, 10).

We fully endorse a contextual approach as the right direction for the field. There is, however, another issue that we want to address here: For decades, phenomenological psychopathology has centered on the "paradigm case" of schizophrenia. Many of the general approaches and theoretical frameworks that now characterize the field as a whole were initially developed with the more specific aim of understanding this condition. Even Pienkos centers her proposal around the study of schizophrenia, showing how a contextual approach can help us understand it as a disorder of both self *and* world. We agree that these phenomenological accounts will be enhanced by a more contextual approach. However, we suggest that continuing to use schizophrenia as a paradigm case of mental illness may not be the most productive route to developing such an approach. Phenomenological work on schizophrenia may have been able to proceed in an acontextual manner because many of the core features of this condition *can* be understood without much attention to context. It may very well be the case that a contextual approach will provide a more nuanced understanding of schizophrenia. But the understanding that we've been able to attain with phenomenological psychopathology's current, more or less acontextual approach is already impressive.

If we truly want to develop a contextual approach to phenomenological psychopathology, why not start from another paradigm case—a condition that can be understood only with a high degree of sensitivity to both social and personal context? We argue that addiction, and substance misuse more broadly, may provide just such a paradigm case, precisely because it cannot be understood acontextually. To illustrate this, we provide a brief vignette and phenomenological analysis. The vignette is a fictionalized composite of substance misuse patients, intended to represent a typical case that should resonate with clinicians. Through this case, we show how the very idea of understanding substance misuse in an acontextual way is a non-starter. Only by attending to specific contextual details of the case—one's culture, upbringing, relations with friends, family, colleagues, environment, and so on—can the phenomenological psychopathologist begin to understand the relevant experiential alterations. To simplify the analysis, we focus exclusively on alterations in selfhood and intersubjectivity. In this respect, we highlight the self-other relation. However, a genuinely contextual approach will of course need to attend to the self-other-*world* relation (11). This would require that that the case be analyzed along other dimensions as well, attending more explicitly to temporal (12, 13) and spatial (14) alterations.

Substance misuse illustrated through a vignette and analysis

Peter, 36 years old and married since he was 23, comes from a poor family marked by many cases of substance abuse, which led to a significant family breakdown. Due to his father's alcoholism, his mother, who was mainly responsible for his upbringing, moved several times between different places and cities, always looking for some stability for the upbringing of her children. Despite his difficult personal history, Peter never saw himself as a sad person. On the contrary, he describes himself as someone who always liked the streets, where he could release his often uncontrolled energy: "I always had a compulsion inside me, something I had to do, to unload. And I didn't know what I had to do, how to control it. I didn't have orientation, someone to say, look, go to a psychologist, so he can orient you on how to spend your energy there." At the age of 16, he started using cannabis, initially aiming to reduce his agitation. He says the fact that his cousins were also using substances made this choice easier. Gradually, he started using other drugs, until he found crack cocaine, with which he lost control and started using it compulsively. He says that crack cocaine is "...very strong, it causes that thing, that ecstasy in you, and the next day you have the need to smoke it again." He always interpreted his misuse as contrary to his personal values: "Even though this feeling [of intoxication] was so strong inside me (the interviewee cries) the next day I would try to use again. So I saw that it was stronger than me. I was losing."He underwent many treatments over the years, alternating periods of control with new and harmful relapses.

Peter is very clear about the intersubjective context related to the loss of control, stating,

> "(...) the only thing I'm afraid of, if I'm going to talk like this, is having a person in my life who doesn't have emotional control. Because I, since I have a problem with emotions, that I think what releases our compulsion, of people like me, that this predisposition is the oscillations of the sentimental, of emotions, so I have to be with a person who is emotionally strong."

In his specific case, he affirms, "My recovery is very much linked to the fellowship that I follow, of narcotics anonymous, which is me, God, and the society that I serve." He also describes precisely what he considers to be recovery from addiction: "The person begins to feel his values again. The emotions come out, the values, family, work, the intellectual part, it all comes back to him. The limits he must have, what he must do, so all this puts the man back in the center. I started to miss my wife and daughter again, to value everything I had."

The above vignette immediately highlights Peter's relationships with the people close to him. While the nature of these relationships may be difficult to describe, many would characterize them as unhealthy or out of balance. From a phenomenological perspective, we can say that they express disproportions in intersubjectivity (15). This is not to suggest that the general or fundamental structure of intersubjectivity is altered (e.g., through a diminished capacity to empathically perceive others). Rather, the relevant disproportion or disturbance operates at a less fundamental level—which is not to suggest that its effects on one's life are any less significant (16).

Peter seems to rely heavily on others when making decisions. Even the simplest decision about his own life constitutes something difficult and risky. He experiences the decision-making process as something too complex to wade through alone. As a result, his autonomy has been gradually replaced by a kind of heteronomy, whereby it becomes difficult for him to control or determine the pathways of his own biographical development or life narrative. Giving someone else authority over the direction of his own life, over his daily decision-making processes, provides a degree of stability and comfort. But granting this kind of authority does, of course, come with its own dangers. His lack of autonomy not only comes with a distressing sense of emptiness, but also makes him exceptionally vulnerable to abuse. Without a strong sense of autonomy and sense of self, he relies on others to help make his day-to-day decisions, but also relies on their view of him to constitute his own value and identity. Ideally, our experiential poles of self and other should be in proportion, allowing the views of others to have some effect on our sense of self and identity while also retaining a degree of autonomy over who we take ourselves to be and what we choose to do with our lives.

One should not, however, understand this disproportion only in a negative perspective, as deprivation of the self. As illustrated above, the right person can help to guard and preserve one's own values; their direction is, effectively, a guiding action that respects and preserves one's own values. That is why mutual help groups are fundamental in the recovery of people with addiction or problems with substance misuse, yielding therapeutic outcomes (17, 18). Through this form of intersubjective association, the emptied person can find someone who, having experienced the same condition, is able to temporarily take the place of a strong person to lead their life. The emptied self may recover through the influence of a strong other who helps them establish and maintain minimally stable values.

But we also see another aspect of intersubjective disproportion in this case: a profound existential submission to a collective, whereby the self can be determined entirely by others. At times, Peter is imprisoned by how the collective values (or fails to value) him. In this disproportion, the self is too sensitive to the perceptions of the collective. Acting in a way that doesn't accord with the collective's values brings about intense guilt. There is thus a direct link between the frequent experiences of guilt of a person with substance misuse and their submission to the social, even in those who do not feel depressed and even take pleasure from the experience of marginality (19). When a person's existence is characterized by this kind of submission, they are pre-reflexively conditioned by set social duties whose values they cannot relativize. They are too exposed to the values prescribed to them and are unable to establish enough distance to constructively reflect on and revise them.

Discussion

How does the analysis of this vignette differ from traditional phenomenological analyses of other conditions, such as schizophrenia? It's not simply that the vignette provides extensive biographical details. In principle, an analysis of schizophrenia could also start from a biographically rich vignette. Rather, the major difference is that an accurate analysis of experiences of addiction and substance misuse requires a constant sensitivity to this kind of biographical context. This kind of approach allows us to consider how and why the person's behavior and experiences differ so dramatically from one context to another. We see, for instance, that when Peter has someone who helps him establish and maintain a strong value system, he can live a life free of substance misuse. In the right context, we may not even perceive him as ill. Without these interpersonal relationships, he falls back into the same harmful behavior. But this is not entirely the product of context, since many people do not fall into these behaviors when placed in the same contexts. Rather, a genuinely contextual approach to phenomenological psychopathology is one that takes seriously how our self-other-world relations shape the very form or structure of our experience.

In this example, the specific kinds of relationships that Peter developed (or failed to develop) with individuals and collectives, as well as his own reflections on the purpose and role of these relationships, are what provides genuine insight into how his experiential life is structured. We have argued that he exhibits an anthropological disproportion in intersubjectivity, where the pole of the other is weighted much more heavily than the pole of the self. And this is precisely why his interpersonal circumstances have the effects on him that they do.

This kind of disproportion, or experiential alteration, also highlights another reason that addiction and substance misuse require a contextually sensitive analysis. Phenomenological studies of psychopathological conditions are often concerned with deep or fundamental alterations in the structure of experience. We might characterize some of these alterations as occurring at the ontological level—that is, they involve changes in what the classical phenomenologists considered to be essential, even invariant, structures of experience and subjectivity (20, 21). However, what we have referred to here as the anthropological level (and might also be called the ontic or empirical level), includes aspects of experience and subjectivity that are less fundamental and more variable from person to person. While these differences and alterations are not as fundamental as, for instance, the loss of conative drive in melancholic depression or the disturbance of minimal selfhood in schizophrenia, they're key to understanding a variety of conditions.

These anthropological disproportions play a central role in the study of substance misuse, as they can inform our understanding of the specific vulnerabilities that lead some people to misuse substances. Identifying these disproportions helps to clarify the meaning that each experience of intoxication has within a person's lived world and understand why intoxication is so attractive to them (22). We can briefly illustrate this point with a particular personality type that is often vulnerable to substance misuse: borderline personality (23). For people with this personality type, the poles between self and other are also weighted heavily toward otherness. Others are therefore able to influence the borderline self in a way that can make it unstable. For example, a person with borderline personality may find it difficult to maintain the same dispositions or life plans when a person who played a dominant role in their life is no longer directly present. To this kind of personality, misusing substances may serve as a viable coping strategy because these substances can provide affective continuity, which allows one to sustain the affective disposition they need to continue one's life projects. Intoxication can therefore compensate for the instability that typically arises out of one's own disproportions.

By taking a contextual approach and attending to conditions that are primarily characterized by disproportions or alterations at the anthropological level, we also arrive at insights that may have more immediate clinical relevance. For instance, a rich understanding of how the structure of a patient's experience shapes his relations and interactions with others is an invaluable resource, not only for the traditional psychotherapeutic encounter, but also for clinical decision-making processes about the most effective programs for treatment and care (14, 24). The vignette and analysis, for example, highlights precisely why narcotics anonymous was an effective therapeutic intervention for him. To understand its effectiveness, we need to attend not only to narcotics anonymous as a specific context that he's placed in (perhaps at the suggestion of his psychiatrist), but also to Peter's personal sensitivities to context—to how he relates to collectives by adopting and incorporating their values.

This is also where a greater focus on Peter's material environment would help us understand his experience and behavior. The social environment of narcotics anonymous may, for instance, be in tension with Peter's material environment, which might provide him with easy access to narcotics. A complete analysis of Peter's case would therefore require a more holistic account of self-other-world relations. While classical phenomenology certainly provides resources for thinking about the role of one's material environment, this may also be an opportunity to incorporate more ecological or enactive approaches to analyze the nature and role of material environments, including how environments affords us a space of possibilities.

If we truly want to pursue a more contextual approach to phenomenological psychopathology, where do we go from here? Adopting a new paradigm case that refocuses our attention on the role of context is only a means toward a further end. It highlights the need for new tools and approaches that help phenomenology better contribute to current needs in mental healthcare. While it's true that some phenomenological psychopathologists have used contextual approaches, many other phenomenological traditions have developed considerably more robust ways of attending to context and socio-cultural situatedness. Within philosophy, we might draw from fields such as feminist phenomenology, phenomenology of race, phenomenology of disability, and critical phenomenology [e.g. (25)]. And, if we look beyond philosophy, to phenomenological approaches developed across the human and social sciences, we also find more empirical applications of phenomenology, such as integrations with qualitative and ethnographic methods [e.g., (26–30)]. We believe that the time is ripe for more integrative approaches to phenomenology, drawing on the rich methodological tools developed across phenomenology's diverse traditions. And closer attention to cases of addiction and substance misuse can facilitate the integration of these approaches with phenomenological psychopathology because they require careful attention to various dimensions of context.

Data availability statement

The datasets presented in this article are not readily available because clinical interview data is not available to be shared publicly. Requests to access the datasets should be directed to guilherme.messas@fcmsantacasasp.edu.br.

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Unrecognized schizophrenia spectrum and other mental disorders in youth disconnected from education and work-life

Line Lindhardt[1]*, Lars Siersbæk Nilsson[2], Povl Munk-Jørgensen[3], Ole Steen Mortensen[4,5], Erik Simonsen[6,7] and Julie Nordgaard[2,7]

[1]Early Psychosis Intervention Center, Mental Health Services East, Psychiatry Region Zealand, Roskilde, Denmark, [2]Mental Health Center Amager, Mental Health Services Capital Region of Denmark, Copenhagen, Denmark, [3]Psychiatric Research Academy, Region of Southern Denmark, Odense, Denmark, [4]Department of Occupational and Social Medicine, Holbæk Hospital, Holbæk, Denmark, [5]Department of Public Health, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark, [6]Mental Health Services East, Copenhagen University Hospital, Psychiatry Region Zealand, Roskilde, Denmark, [7]Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen, Copenhagen, Denmark

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EDITED BY
Rosa Ritunnano,
University of Birmingham,
United Kingdom

REVIEWED BY
Jordan Sibeoni,
Université de Paris, France
Michele Poletti,
IRCCS Local Health Authority
of Reggio Emilia, Italy

*CORRESPONDENCE
Line Lindhardt
linli@regionsjaelland.dk

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Background: Schizophrenia spectrum disorders typically emerge during adolescence or early adulthood. Often the symptomatology is vague initially, while a marked functional decline and social withdrawal can be seen. A group of young people with such social and functional impairments is the so-called "Not in Education, Employment or Training" (NEET), i.e., a youth population that is socially disconnected from education and work-life. Despite the NEET group's disconnection from important parts of social life and a rising concern of an intersection with mental health problems, a psychopathological perspective on the problems experienced by this group remains underexplored.

Aim: To examine a NEET sample for psychopathology and if relevant allocate psychiatric diagnoses.

Methods: We performed an interview study comprising 40 participants from youth job-counseling services. All underwent a comprehensive psychiatric evaluation. Inclusion criteria were 18–29 years of age and a welfare benefit history of minimum 6 months.

Results: Diagnostic criteria of any mental disorder were fulfilled by 95% of the sample; half of whom were diagnosed with a schizophrenia spectrum disorder. The participants with schizophrenia spectrum disorders had lower global functioning, were more often in contact with the mental health services and had higher PANSS and Examination of Anomalous Self-Experiences (EASE) scores compared to those with non-schizophrenia spectrum disorders. The participants fulfilling the criteria for schizophrenia spectrum disorders had lower EASE and PANSS scores than usually reported in the literature, suggesting more "symptom-poor" presentations.

Conclusion: Psychiatric illness and particularly schizophrenia spectrum disorders affecting social interaction and the ability to take part in educational and work-life were grossly overrepresented in the NEET sample. Our findings suggest that pronounced social disconnection in youth in and of itself should lead to suspect the presence of a severe mental disorder.

KEYWORDS

schizophrenia spectrum disorder, NEET, psychopathology, social disconnection, psychosis

Introduction

Social disconnection in the general youth population results in marginalization for the individual, and has considerable economic consequences for society (1). Consequently, socially marginalized youth is a major public health concern with social policy interest (2, 3). The term "Not in Employment, Education or Training" (NEET) is an international consolidated indicator and among others used by Eurostat and the Organization for Economic Co-operation and Development to describe school-to-work transition difficulties in a vulnerable population of youth facing "social exclusion" (4–6). The concept of NEET has been adopted by researchers and governmental officials to define disconnection from education and work-life in the youth population (3, 7).

Obviously, there are societal differences such as dissimilar opportunities in education and work-life and social inequality which must be taken into account when looking at NEET from a global perspective (8, 9). Moreover, particular culture-bound forms of severe social withdrawal with underexplored relations to more well-defined mental disorders have been reported, cf. the Japanese phenomenon of hikikomori (10, 11).

Studies suggest, however, that mental health problems may be common denominators of the NEET population irrespectively of country and cultural setting and after controlling for possible confounding factors such as social disadvantage (7, 12–14). Unfortunately, not much is known about mental health problems in young, non-help-seeking NEET individuals.

It is primarily large surveys and health outcome data in population-based studies that have addressed the issue (13, 15–18). They have demonstrated significant associations with depressive symptoms, anxiety symptoms and substance use (13, 15, 18) and, that NEET status in young adults is associated with mental disorders in childhood and adolescence (7, 14, 19). A recent systematic review and meta-analysis by Gariépy et al. showed that the NEET status population had an odds ratio (OR) of 1.43 for having mood disorders, an OR of 1.55 for anxiety disorders and an OR of 1.72 for any mental disorder. However, the study pointed to the need for more knowledge about mental health and NEET status. Especially pertinent is the absence of studies addressing psychotic disorders in the NEET status population (20, 21). On the other hand it is well established that young adults experiencing a first-episode psychosis, are often disconnected from education and work when entering into contact with the mental health services (22–24).

Still, social disability tends to be overlooked or perhaps even outright neglected as a characteristic and important sign for schizophrenia spectrum disorders (25). This is especially relevant in symptom-poor schizophrenia in which a prominent decrease in social functioning is often among the first signs of evolving illness (26). In a 20-year longitudinal study comprising information from 485 patients Velthorst et al. found severe and persistent social impairment to be common in the schizophrenia spectrum disorder course (75%) (27).

Critics have pointed to initiatives in early detection of psychosis not taking the significance of social impairment or functional decline fully into account and as such young people with the NEET status are suggested to be a candidate group for early intervention and preventative strategies (28, 29). By thoroughly exploring psychopathology in a NEET population our understanding of the barriers for engaging in social and work life in such groups could be widened.

Aims

To investigate psychopathology outside the boundaries of the mental health system within a group of NEETs, and allocate a diagnosis if relevant. Additionally, to further examine the clinical characteristics of the NEETs.

Materials and methods

Study population

The NEET population was recruited from municipality job-counseling centers within local government social services. In Denmark, young people not in work or education are entitled to financial support if they cannot support themselves. The organization of the assessment of rights to claim financial assistance, is governed by the municipalities and organized in job-counseling centers within the social services (30). Usually, a prerequisite for receiving such financial support is partaking in meetings in the job-counseling centers and non-participation customarily results in the loss of this entitlement (31). Thus, the vast majority of NEETs are in contact with the job-counseling centers.

The participants were recruited from three municipality job-counseling centers of the region Zealand of Denmark: Roskilde Municipality (89,000 inhabitants), Køge Municipality (60,000 inhabitants) and Stevns Municipality (22,000 inhabitants). The catchment areas of these municipalities are primarily rural or suburban.

The following inclusion criteria were applied:

1. Aged 18–29 years
2. Had received non-medical welfare benefits for at least 26 consecutive weeks before the invitation to the study
3. Fluently Danish-speaking

The age range corresponded to the organization in the Danish job-counseling centers, with some organizational differences between municipalities, with specific teams handling the 18–29 year-old young adults. In this study, NEET was defined as a duration of more than 26 consecutive weeks receiving educational benefits, thereby ruling out the possibility of a more transient state of disconnection. Eligibility for participation was independent of prior or current psychiatric treatment.

Recruitment procedure

The participants were recruited by case workers in the three municipalities, who were asked to invite all young people in the job-counseling centers fulfilling the inclusion criteria. Collaboration with the caseworkers in the social services was established by in-person meetings with the teams of caseworkers handling the youth population seeking social assistance. If the invited candidates accepted, the first author LL contacted them by phone. The interviews were conducted either in a municipality facility or in the local outpatient mental health clinics, depending on the participant's preference. All participated upon informed consent. The recruitment and inclusion of participants are presented in **Figure 1**.

Assessment

The psychopathological and diagnostic interview included:

- Operational Criteria Checklist for Psychotic Illness and Affective Illness scale (OPCRIT) (32) [an extract of the Present State Examination (PSE)].
- Positive and Negative Syndrome Scale (PANSS) (33).
- Bonn Scale for the Assessment of Basic Symptoms (BSABS), the perceptual section (34).
- Assessment of the First Rank Symptom continua (35).
- Examination of Anomalous Self-Experiences (EASE) (36).
- Global Assessment of Functioning scale, the split version (GAF-S and GAF-F) (37, 38).

The composite of scales derived from former studies exploring schizophrenia spectrum psychopathology and differential diagnosis (39–43). The participants were also assessed with respect to life history, overall psychosocial functioning, educational and vocational history including periods of welfare benefit dependence, family history of mental disorders, and the history of contact with mental health professionals, mental illness evolution and history of somatic diseases and physical symptoms with consequences for overall functioning.

EASE, a symptom checklist consisting of 57 main items, was used to explore anomalous self-experiences (36). In accordance with previous publications, the EASE items were scored only present or absent, not including severity or frequency, and subtypes were collapsed into main items (41, 44).

The timeframe for the assessment of all the scales, other than PANSS and GAF, was lifetime. The timeframe of the PANSS was, as specified by its authors, "the previous week" but did not include descriptions by peers and surrounding professionals (33). The GAF was evaluated as current state at the time of evaluation (45). The interviews were split into several sessions if needed, depending on the participant's capability. In such cases, the interview sessions were conducted with a short interval and within a maximum of a few weeks. The interviews were conducted between 1st April 2019 and 1st January 2021.

All interviews were either videotaped or audiotaped. The interviews were semi-structured, conversational, and phenomenologically orientated, encouraging faithful self-descriptions (39, 40). Items were only rated as present if the participants provided descriptions and examples that fitted a relevant item definition, i.e., an item was not rated as present based on a simple "yes" answer. All interviews were completed and there were no missing data.

The interviews were performed by the LL, an MD with several years of experience in clinical psychiatry, certified in the application of the EASE, and tested for interrater reliability for the EASE prior to the study with JN, a senior psychiatrist and researcher and certified EASE instructor (interrater reliability $\kappa = 0.75$). Further the interviewer LL is a PSE instructor at regular courses. Average duration of interviews was 4 h [range: 2 h and 45 min–7 h and 0 min].

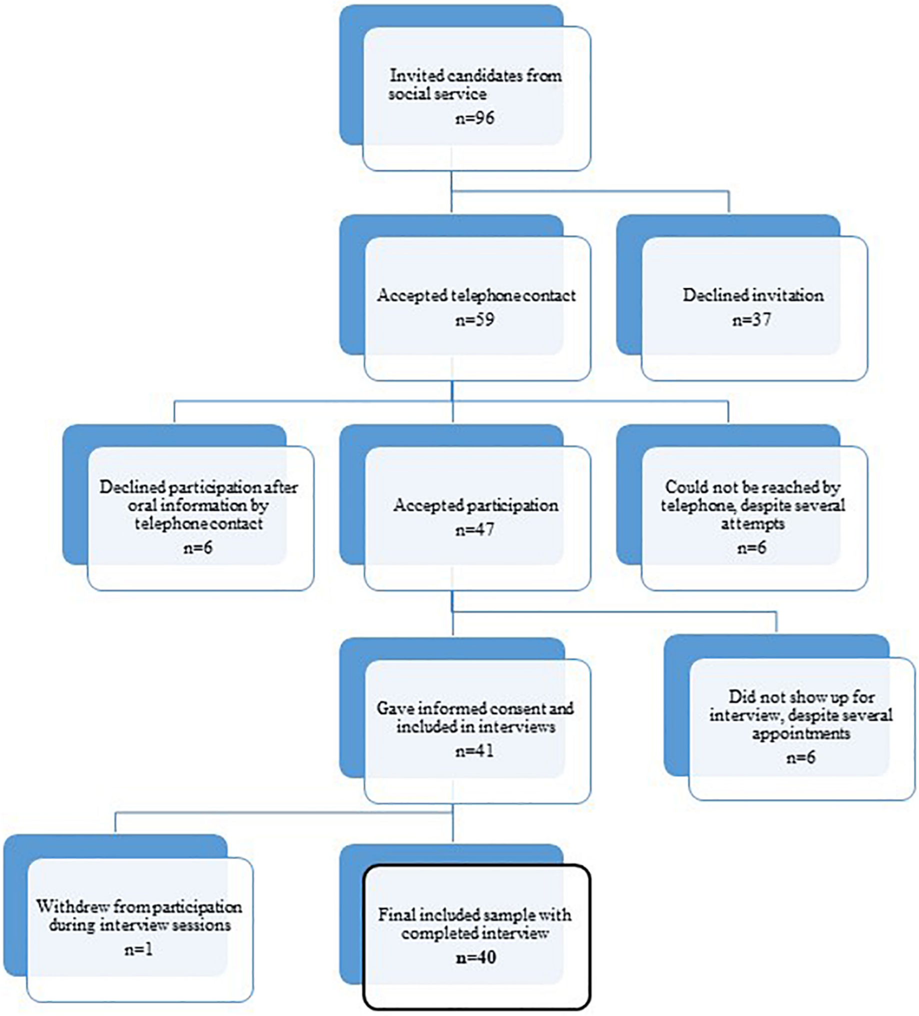

FIGURE 1
Flow of study participants.

Finally, all patients were allocated a "Best-Estimate Life-Time" ICD-10 diagnosis by LL. If any uncertainty about psychopathological phenomena or diagnosis occurred, JN or LSN, an experienced MD and certified EASE instructor, were consulted and extracts of interview recordings were evaluated jointly to reach consensus. Additionally, randomly selected videotaped interviews were jointly evaluated with respect to general psychopathology, EASE items, and overall consensus of best-estimate life-time diagnoses. In total, consensus ratings were performed in 26 (65%) of the included interviews. All items were rated conservatively i.e., if the presence of an item was considered doubtful, this item was consistently rated as absent.

If the participants reported any lifetime substance use, the diagnosis of schizophrenia, non-affective psychosis or schizotypal disorder was only made if the psychopathology could convincingly be related to periods in which the individuals had not used any substances for more than 6 months of abstinence or significant psychopathology present prior to onset of substance use.

Diagnostic grouping

We grouped the diagnoses according to the ICD-10 hierarchy with (1) schizophrenia and non-affective psychosis; (2) schizotypal disorder; (3) other mental disorders; (4) no mental disorder.

Ethics

The study was evaluated by the National Committee on Health Research Ethics, journal no. 18-000080, and was concluded not to fall under the Health Research Act. The study was approved by the Danish Data Protection Agency, journal no. REG-064-2018.

If mental disorders requiring psychiatric treatment were identified during the interviews, the participants were referred to a relevant mental health service.

Statistical analyses

We dichotomized the diagnostic variables by merging the data into diagnostic groups of schizophrenia spectrum disorders, i.e., schizophrenia, non-affective psychosis and schizotypal disorder (43), and a group of other mental disorders. We tested for association between schizophrenia spectrum disorder and social functioning as measured by GAF-F, GAF-S, and total PANSS sum score applying *t*-test. The assumption of normal distribution was tested using Shapiro-Wilk test. The GAF-S and GAF-F scales were scored as continuous scales (37). For the variables GAF-F score and PANSS sum score the assumption of normal distribution was not fulfilled, and we therefore used the non-parametric Wilcoxon Signed Rank test to test for differences between groups.

We used ANOVA to compare EASE mean scores between the diagnostic groups (schizophrenia, schizotypal disorder, other mental disorder, and no mental disorder). We corrected for multiple testing by Scheffe's test (46).

All analyses were conducted using SAS Enterprise Guide 7.1. Significance level was set to 0.05.

Results

A total of 40 participants were included in the study with a mean age of 24 years, 53% male.

The typical participant had received non-medical welfare benefits for more than 1 year (mean 90 weeks, range [27.8–317.3]), had in at least one prior period received non-medical welfare benefits (n = 26, range [1–7 episodes]), and had an educational level of compulsory education or less (48%). In the majority of cases, there was a history of frequent disruptions to educational plans or vocational attachments (73%). In addition, the typical participant lived alone and was not in a relationship (55%), had parents that suffered from mental disorders or substance use problems (71%), and the participant had been in contact with mental health services in childhood or adolescence (42%). About one third had not completed final exams in compulsory school (30%). The sample had mean GAF-F 49.0 (IQR: 45.0–58.0).

We found that 38 (95%) participants fulfilled the criteria for a lifetime diagnosis of a mental disorder, and 21 (53%) were allocated a diagnosis of schizophrenia spectrum disorder. More specifically 10 participants fulfilled the diagnostic criteria for schizophrenia, 9 for schizotypal disorder, and 2 for unspecified non-affective psychosis. The distribution of disorders among the sample is presented in **Figure 2**.

Only 2 participants did not meet the diagnostic criteria of any mental disorder. One of these was newly diagnosed with a chronic somatic disease that explained the reduced ability to engage in education and work. The other was during his school years suspected of having an attention deficit disorder, but the diagnostic outcome of the prior mental examination remained unclear. The interview revealed only vague symptomatology with social withdrawal as the most prominent finding, and no diagnosis of any mental disorder could be allocated in the present study.

For two participants, clear psychopathological phenomena were only present during periods with ongoing substance use, and they were therefore only assigned a diagnosis of substance use.

The schizophrenia spectrum disorder group

Among the 21 participants who were diagnosed with a schizophrenia spectrum disorder in the study 14 were already in contact with the psychiatric services: 5 of those were diagnosed with schizotypal disorder, 2 with schizophrenia and 7 with a non-schizophrenia spectrum disorder.

The participants who fulfilled the criteria for a schizophrenia spectrum disorder had mean EASE score of 11.8 (*SD*: 1.7). The EASE mean scores were significantly higher for participants with a diagnosis of schizophrenia, other non-affective psychoses or schizotypal disorder than for participants with other mental disorders and no mental disorders (**Table 1**). Correspondingly, participants with schizophrenia spectrum disorders scored lower than participants with other mental disorders on GAF-F [median: 48.0 (IQR 41.0–50.0) vs. 55.0 (IQR 49.0–69.0)] and GAF-S [mean 52.1 (SD 11.3) vs. 64.8 (SD 8.0)] and higher on PANSS [median 50.0 (IQR 40.0–57.0) vs. 34.0 (IQR 31.0–41.0)]. The median PANSS positive score was 11.0 (IQR 7.0), the median PANSS negative score was 11.0 (IQR 7.0) and the median PANSS general score was 25.0 (IQR 9.0) in the subgroup.

Clinical case illustrations

We here present two illustrative cases from the schizophrenia spectrum disorder group.

Case 1

A 28-year-old female grew up in a family of four. She had social difficulties throughout childhood and adolescence; she had no friends and became anxious around other people. She had a hard time keeping up with the schoolwork and did not have any interests. She finished high school with low grades,

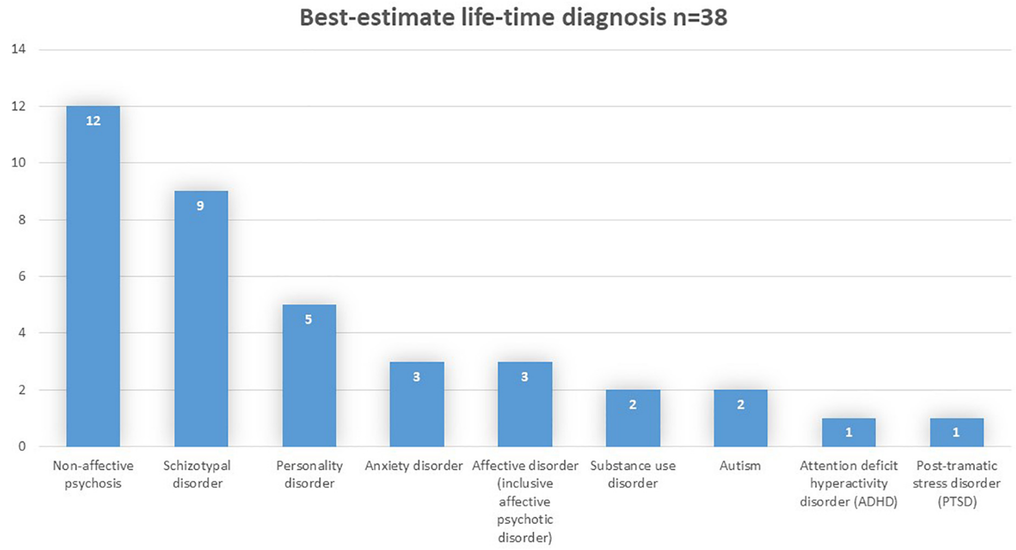

FIGURE 2
Distribution of mental disorders.

TABLE 1 Distribution among the study population of diagnoses allocated by assessment, previous lifetime clinical diagnoses, and EASE scores.

	ICD-10 diagnoses			
	Schizophrenia and non-affective psychosis	**Schizotypal disorder**	**Other non-schizophrenia spectrum disorders§**	**No diagnosis of any mental disorder**
Best estimate lifetime disorders by assessment (n)	12	9	17	2
Diagnoses clinically assigned previously, lifetime (n)	2	5	24	9
EASE$^{\alpha}$ mean score (SD)	13.4 (6.0), [4–24]*¤	12.8 (5.2), [4–13]*¤	4.4 (3.5), [1–12]	0.5 (0.7), [1]

§Mental disorders not belonging the schizophrenia spectrum (schizophrenia, schizotypal disorder) or non-affective psychosis and includes substance use disorder. *Difference in mean compared to the group assessed not to fulfill criteria of any mental disorder lifetime ($p < 0.05$). ¤ Difference in mean compared to the group assessed to fulfill criteria of any lifetime non-schizophrenia spectrum disorders inclusive substance use disorder ($p < 0.05$). $^{\alpha}$Examination of anomalous self-experiences.

partly because she had a depressed period after a break-up with a boyfriend. She dropped out of university after a few months. Later, she moved in with a friend and tried four times to start an education but dropped out repeatedly.

She was assessed in the mental health services under the diagnosis of social anxiety and started psychotherapy in group sessions but withdrew because she was unable to be in sessions with others.

For 3 years she had experienced the presence of a male person sitting on her shoulder, talking into her ear with criticizing statements about her and giving her commands that she felt obliged to obey. Still present, and reaching back as long as she could remember, she had felt the constant presence of yet another person and described herself as spiritually "open to anything." She never felt that she had any real purpose or meaning in life and often questioned a lot of things seemingly without any special relevance to her: "Why do we have doors, is that really smart? Or who invented the door? Is the color of the door the same to me as it is to you?" Often, she would hear her name being shouted out loud. On a daily basis she experienced thinking about random experiences that seemed to be of no specific relevance to her, but nonetheless would play over and over again, even though she tried to get rid of them. Such thoughts would often play out like an inner picture or movie. She wondered if the world was real or "just a dream in some way," and when standing on the railway station she might ponder if the people in the train would still exist, when she could no longer see them.

Auditory hallucinations and delusions had thus been present for more than 3 years. Currently, she experienced ongoing vague auditory hallucinations and negative symptoms. Additionally, she described *Anwesenheit*, a diminished sense of basic self, loss of common sense, social anxiety, primary self-reference, ambivalence, perceptual disturbances, mirror-phenomenon, hyperreflectivity, and solipsistic experiences. Her EASE score was 19, PANSS 37, GAF-S 50, and GAF-F 45. Best estimate lifetime diagnosis: Paranoid schizophrenia.

Case 2

A 22-year-old male grew up with his mother, who suffered from periodic depression, and he only saw his father on rare occasions. In school, he had anger management issues, but later he became more withdrawn. He had social difficulties and ended up playing computer games and not attending school. He moved to live with his mother's sister due to problems at home. At age 16–18, he was seen in a child and adolescent psychiatric outpatient clinic and was diagnosed with an attention deficit disorder. Medication helped somewhat on his concentration in school. He went to boarding school, where he had one close friend. He was seen twice in the psychiatric emergency department with suicidal thoughts during this period. He was enrolled in a vocational track in higher education but never showed up. The job-counseling center arranged a traineeship in a shop, which he attended for 4 months but with frequent absence—"then the whole thing went haywire." He was diagnosed with depression at age 19 and 1 year later he was hospitalized after a suicidal attempt and diagnosed with acute stress reaction.

Social interactions scared him, as he feared to catch people's attention. He described having many scary thoughts which he initially refused to elaborate on, but whose physical location he showed by placing his hand at the back of his head. After a break in the interview he described further that those "scary thoughts" placed in the back of his head included hearing an ongoing voice, which was not his own, talking to him and addressing his appearance in a devaluating way, always naming him in second person, for instance "you are a bad person." The voice was described as being "just on repeat." In addition, he described the voice as being out of his control which scared him. He was not able to reflect further on the experience and in the following just referred to it as "bad thoughts."

He described auditory hallucinations for at least several months, perhaps longer. He did not describe symptoms of affective disorder, bur harbored pronounced negative symptoms. Additionally, he described spatialization of experience, hyperreflectivity, social anxiety, self-reference, and thought pressure, but had major difficulties verbalizing his psychopathological experiences. His EASE score was 5, PANSS 56, GAF-S 45, and GAF-F 41. Best estimate diagnosis: Non-organic Psychosis Not Otherwise Specified.

Discussion

We examined a NEET population recruited from outside the mental health services for psychopathology and found that almost all participants qualified for a diagnosis of a mental disorder and that schizophrenia spectrum disorders were the most common. The 53% of the participants, who suffered from a schizophrenia spectrum diagnosis, had higher EASE mean scores and lower global functioning than the rest of the sample.

One third of the participants met the diagnostic criteria for an ICD-10 schizophrenia spectrum disorder but they were not in contact with the mental health services. More than half of the participants who fulfilled the diagnostic criteria of schizophrenia spectrum disorders were in contact with the mental health services but diagnosed with disorders outside this spectrum.

This could reflect that the subgroup meeting diagnostic criteria for schizophrenia spectrum disorders in our sample was less symptomatic than many other schizophrenia spectrum samples described in the literature. This is illustrated, e.g., by a low median PANSS total score of 50.0, which is on par with scores often reported at discharge from psychiatric admissions in schizophrenia spectrum cohorts (47, 48). The mean EASE score of 11.8, is lower than found in studies examining patient samples though one study reported a mean EASE score of 15.5. The most recent systematic review reported a total mean EASE score of 20.7 and 19.7 for schizophrenia and schizotypal disorder, respectively (49).

This low level of symptomatology could perhaps be explained by the illness being in an early phase at the time of the assessment in our study. This explanation is in line with the fact that a decline of social functioning often precedes the development of more obvious psychopathology in these disorders (26, 50). However, it is also well-established that a significant proportion of schizophrenia spectrum patients come across as relatively symptom-poor (51). Eugen Bleuler, who famously coined the concept of schizophrenia, explicitly noted that even manifestly ill patients may at a given time harbor—or at least be able to verbalize—rather few clear-cut symptoms. This, Bleuler noted, poses a significant diagnostic challenge, "because the attending physician cannot testify to the presence of mental disease, or because even if he has testified to it, the director of the mental hospital will occasionally release the patient as well or cured to the dismay of the desperate parents" (52) (p. 296). The existence of such symptom-poor schizophrenia spectrum patients, and the diagnostic conundrums they comprise, is addressed by several other classic psychopathological texts and clinical concepts (53–56). For example, Zilboorg described how such vaguely symptomatic patients, suffering from what he termed ambulatory schizophrenia "seldom reach the psychiatrist's office for many reasons. First, they are considered by both the laity and the medical profession as merely weak people, "poor personalities," "psychopathic personalities," whatever these words may mean" (57) (p. 154).

Indeed, as noted by both Bleuler and Zilboorg, an ordinary clinical encounter with such a patient may reveal nothing particularly remarkable and raise no clear suspicion of a schizophrenia spectrum disorder. On the contrary it often takes an in-depth conversational interview that encourages the patient to reflect and elaborate on his experiences—and sometimes prolonged observation—to reach a valid diagnostic evaluation (39). This, however, is not just a time-consuming process, but also one that presupposes a great deal of clinical experience and sophisticated psychopathological knowledge on the part of the interviewer, all of which may be in short supply in contemporary clinical practice (58).

Importantly, self-disorders also play out in the intersubjective sphere. For example, many persons with self-disorders struggle with the experience of somehow being ontologically different that other people, or "not really human" (59) (p. 94) (i.e., diminished sense of basic self in the EASE). It seems to us that struggling with such experiences of profound dissimilarity might make it quite difficult to engage in social activities with others. Another example could be disturbances of the first-person perspective and hyper-reflection that in some cases lead to excessive forms of self-monitoring which operate alongside the person's engagement with others thus impeding natural, effortless social interaction (60–62).

The population investigated in this study was not primarily help-seeking in the mental health services but was identified based on their claim of welfare benefits. In the Danish context, social caseworkers are the assessors of qualification for such claims and they are responsible for the evaluation of the young person's current ability to participate in ordinary education or work. If there are coexisting difficulties, e.g., mental health problems, that hinder this process, the young person is entitled to a coordinated effort aimed at alleviating the problem at hand (30).

However, the complexity of this task seems undervalued. The severe mental health problems found among the NEET population demonstrate the difficulties that social caseworkers with no psychiatric training are faced with. As such they highlight the inherent problems in the physical and organizational separation of the social and mental health services that might, as pointed out in a BMJ editorial, result in insufficient attention being paid to the "double whammy" of NEET status and severe mental disorder (5, 63).

Our findings of a large proportion of schizophrenia spectrum disorders lend support to the guideline proposed by Meehl that a young individual's gross underachievement seemingly unexplained by relevant factors should—in and of itself—lead the clinician to suspect a schizophrenia spectrum disorder (64). It should prompt a comprehensive differential-diagnostic evaluation as a first glance paucity of overt symptomatology does not rule out the presence of serious mental illness. As noted by Hoch: "A snake in the grass is not a "latent" snake nor a "larval" snake; it is a snake. And it is not concealed by the grass if one looks for it" (65) (p. 724).

This point seems of particular importance to the NEET population, which may be retained in an already disadvantaged position by ineffective psychiatric treatment and inaccurate evaluations in the job-counseling service, if psychotic disorders are not properly detected.

Strengths and limitations

The principal strength of this study is the comprehensive phenomenological interviews performed by an experienced clinician and the consensus ratings of the psychopathological material. Further, the study was carried out with few exclusion criteria in the real-life setting of a job-counseling center thus enhancing external validity. The ratings were conservative and if it was doubtful if items were present, this item was consistently rated as absent.

The main limitation, on the other hand, is the small sample size. This is a feature of the study's design with lengthy interviews but also reflects its setting and target group. The study did experience recruitment difficulties with inefficient invitation by the caseworkers among the eligible participants in addition to difficulties in establishing contact with those eligible participant who had accepted the invitation to join. Former studies have described similar difficulties when recruiting among the inactive youth population (66, 67).

It cannot be ruled out, that there was a selection bias built into the invitation procedure of the study, with the caseworkers perhaps being more prone to invite participants whom they believed to be in need of psychiatric assistance. However, the possible effect of such a bias is not univocal. It could be that those not invited were more difficult to reach with an even lower level of functioning and thus, assumingly, an even greater risk of severe mental health problems. Investigating the NEET youth population in a job-counseling center could itself have a built-in selection contributing to the findings of low levels of obvious symptomatology. One could suspect that an even more disadvantaged NEET population with more severe symptomatology might never reach the job-counseling center.

Including NEETs that were already known to have mental disorders in this study did affect the results i.e., a small part of the sample was already previously diagnosed with schizophrenia spectrum disorders. On the one hand, excluding the subjects that were previously diagnosed with mental disorders might have given a more accurate estimate of unrecognized mental disorders. But on the other hand, we found some of the schizophrenia spectrum disorders to be unrecognized among NEETs who had been misdiagnosed with disorders outside the spectrum. Another limitation was the inclusion criterion requiring participants to be fluently Danish speaking. However, this was considered a necessary means to ensuring meaningful participation in in-depth phenomenological interviews.

Conclusion

The psychiatric examination of a NEET youth sample in a job-counseling service setting revealed that 95% qualified for a diagnosis of any mental disorder. More than half of the sample was diagnosed with a schizophrenia spectrum disorder. The schizophrenia spectrum disorders among the studied sample had a symptom-poor presentation with low PANSS and EASE scores. These findings suggest that pronounced social disconnection in youth—in and of itself—should lead to the suspicion of a serious mental disorder.

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 Danish National Committee on Health Research Ethics, journal no. 18-000080/Danish Data Protection Agency, journal no. REG-064-2018. The patients/participants provided their written informed consent to participate in this study.

Author contributions

LL collected the data, performed the statistical analyses, and wrote the first draft of the manuscript. LL, LN, and JN performed the data management. JN and LN contributed to the writing of the manuscript. All authors participated in designing the study, contributed to the revision of the manuscript, which in its present version has been approved by all authors.

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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EDITED BY
Jérôme Englebert,
Université Libre de Bruxelles, Belgium

REVIEWED BY
Haohao Yan,
Second Xiangya Hospital, Central South University, China
Elizabeth Pienkos,
Clarkson University, United States

*CORRESPONDENCE
Miraj Desai
✉ miraj.desai@yale.edu

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A return to lived experiencers themselves: Participatory action research of and by psychosocial clubhouse members

Lester Vescey[1], Jennifer Yoon[1], Kevin Rice[1], Members of PARCO Group[1], Larry Davidson[2] and Miraj Desai[2]*

[1]Fountain House, New York, NY, United States, [2]Program for Recovery and Community Health, Yale Department of Psychiatry, New Haven, CT, United States

Introduction: Within the history of psychology and phenomenology, people with lived experience of mental illness have often served as participants in research, but far less as co-researchers themselves. There is now a growing movement focused on "participatory" research, where people with lived experience directly contribute to various stages of the research process. This article presents such a qualitative, participatory research study, led by members of a large psychosocial rehabilitation clubhouse—Fountain House in New York City—and informed by phenomenological research principles. The study focused on collaboratively assessing and improving the clubhouse program for its members.

Methods: A key feature of the project was the extent of lived experiencer involvement, for instance, in designing and conducting the study, and co-writing this research report. Members of Fountain House were trained in phenomenologically-informed research methods and developed a research study that focused on the quality improvement of their clubhouse program. Member researchers conducted a series of focus groups with fellow clubhouse members, generating qualitative data that were analyzed and written up by member researchers in collaboration with staff and university partners.

Results: Overall, study findings place emphasis on the theme of action in members' experiences—both with respect to how action, agency, and valued activity were key drivers of meaning and recovery for people facing severe mental illness, and with respect to the key component of the research process itself [i.e., participatory action research (PAR)]. Four major subthemes emerged from the study. First, findings revealed how members with mental illness experienced the clubhouse as a "new hope" and "the place for me," to counteract their experience of inactivity, stigma, depression, and hopelessness prior to that point. Second, findings showed how, as members' life goals changed, so did the precise meaning and role of Fountain House in their lives. Third, findings portrayed members' need for, and pursuit of, transformation within the clubhouse space itself to provide more opportunities for meaningful work rather than what they viewed as merely busy-work. Finally, member researchers viewed their direct participation in this project as an opportunity to actively combat stigma, to be a driver of research, and to engage in what they viewed as a generative activity.

Discussion: These action-oriented themes serve as a counter to the historical view of people with mental illness as merely passive experiencers of symptoms and passive recipients of mental health care. We discuss how the process and content of participatory research can help enhance the relevance of research for stakeholders' lives and contexts.

KEYWORDS

participatory research, clubhouse, mental illness, phenomenology, psychosocial rehabilitation

1 Introduction

Persons with lived experience of mental health conditions have long advocated for research and knowledge about mental health to better reflect the realities of their own everyday lives. Indeed, people who have histories of mental illness are taking more active roles in studies pertaining to them, consistent with the rallying cry of the disability rights movement of "nothing about us, without us" (Charlton, 1998). One central way that greater inclusion and representation is taking hold is through the direct participation of persons with lived experience on study teams and research projects (Wallcraft et al., 2009; Davidson et al., 2010; Case et al., 2014; Desai et al., 2019). Participation in all aspects of the research by the community of interest as evaluators and collaborating investigators not only contributes to the empowerment of the persons within the community but also improves the validity and relevance of research findings (Hancock et al., 2012). A formalized research method that embodies these participatory principles is known as participatory action research (PAR), which acknowledges that expertise comes in many forms and seeks to involve members of the community of interest from the very beginning of developing research projects, all toward actionable ends (Lawson et al., 2015; Kidd et al., 2018; Chevalier and Buckles, 2019; Israel et al., 2019).

Settings within the mental health landscape that may be especially well-suited to PAR are mental health clubhouses (Pernice-Duca and Onaga, 2009; Hancock et al., 2012; Pardi and Willis, 2018). Clubhouses are intentional recovery communities informed by the rehabilitation principles of community integration, personal empowerment, and access to social support. These communities, which exist in over 300 locations around the world, invite people with histories of severe mental health challenges (e.g., schizophrenia spectrum disorders, affective disorders, and other severe psychiatric conditions) to work in unison with professional staff to carry out the duties, maintenance, and organization of the clubhouse milieu therapeutic model (Doyle et al., 2013). Thus, the underlying tenets of the clubhouse model share many principles with the PAR ethos (McKay et al., 2018), seeking to combat stigma in mental illness by empowering its members (not "patients" or "clients") to participate in and take ownership of their recovery community by achieving the social, financial, and vocational goals of the membership through mutual and staff support (House, 1999).

Since 2017, members of the original mental health clubhouse, Fountain House in New York City, have been engaged in a PAR training and research project. The long-term goal of this project was to develop a member-led evaluation component within Fountain House that can illuminate the experiences of members and improve the quality of the clubhouse itself. The project has featured members being trained in and then conducting all aspects of a qualitative research study, informed by phenomenological research principles (Davidson, 2003). This includes designing interview questions, conducting and transcribing interviews, analyzing the narrative data, and leading group discussions to synthesize and create a report of the results. We further describe the relationship of phenomenology to our specific research approach in the section "2.3 Analysis." A related quantitative survey study was also conducted and will be reported on elsewhere. This initial training and research project has led to the formation of a standalone Research and Knowledge Team at Fountain House that continues to pursue member-led participatory projects.

This paper represents a robust step in the process of clubhouse members conducting their own research and providing direction to the clubhouse for what will improve their lives and the lives of their fellow members. The approach may differ from many extant psychological and psychiatric studies, including phenomenological ones, given the sheer extent of the involvement of people with mental illness. In the present study, the member researchers themselves conducted focus groups with Fountain House members, focusing on topics selected by the participating member researchers, with a final topic selected by members of the Fountain House Board (as described in section 2.2). After conducting the member-led focus groups, Fountain House members trained in qualitative research methods analyzed transcripts of the focus groups. The participating member researchers then organized their findings into narrative summaries that elaborated the salient, consistent, and unique themes discussed in the focus groups. The findings of this initial study are summarized in the present paper, co-written by clubhouse members, staff, and university-based partners.

2 Materials and methods

2.1 Setting

The project was conducted at Fountain House in New York City and received ethical approval from both Fountain House and the university-based partners' institution. Founded in the 1940s, Fountain House originated the clubhouse model of mental health, seeking to combat the stigma of mental illness by helping members achieve their social, financial, and vocational goals through an evidence-based model of empowerment, mutual support, and (co)operative administration of the clubhouse community (House, 1999; Gold et al., 2016; Raeburn et al., 2016; Hwang et al., 2017). Membership at Fountain House is voluntary, available for life, and is offered to any person with a history of serious mental illness. There are on average 1,300 active members of Fountain House, often with diagnoses of schizophrenia, schizoaffective, bipolar, and major depressive disorder.

Fountain House programs include internal research units, employment supports, administration, health and wellness, supported education, housing assistance, and other social supports idiosyncratic to each of the over 300 credentialed clubhouses in the United States and around the world (for credentialing criteria see Propst, 1992). Central to the clubhouse model is that members participate in the operations and decision making of the clubhouse program through a structured "work-ordered-day," wherein they join a unit or department within the clubhouse (e.g., research, wellness, education, employment, etc.) to work side-by-side with peers and professional staff in conducting the unit's services and operations (Tanaka and Davidson, 2015). These facilitated experiences of shared contribution drive what the clubhouse calls the *need to be needed* (Mancini, 2006), with a focus on rehabilitating member agency, self-confidence, and social acceptance through the structured development of social relationships and community stakeholdership. This therapeutic model of clubhouses is known as social practice, wherein peers and staff leverage the shared work, administration, and social relationships of the community to engage members in their own recovery while combatting the debilitating social stigma and isolation that many with severe mental illness endure in life (Sacks, 2009).

2.2 Procedure

Over the course of one academic year in 2019, members of the Fountain House research unit were trained in the methods of developing research questions, conducting focus groups, and applying qualitative analysis, by university-based researchers with extensive combined experience in qualitative, phenomenological, and participatory research. Participating member researchers first decided what issues they wanted to investigate and communicated these research questions to the university-based team of trainers. The university-based trainers supported participating members in the recruitment of voluntary participants for focus groups through announcements and sign-ups made at a community meeting held weekly at Fountain House. Inclusion criteria were that participants must be a member of Fountain House, be older than 18 years of age, and be capable of providing informed consent. A total of 12 members participated in the study ranging in age from 18 to 70 and ranging in length of membership from under a year to decades. They provided their informed consent to participate in the study. Each participant, by virtue of their being a clubhouse member, had a history of mental illness. Specific diagnoses for each participant were not recorded as the clubhouse model does not differentiate its services based upon a person's specific diagnosis, and since it was fellow members leading the research study, disclosing this information was deemed as unnecessary and a privacy issue amongst fellow clubhouse community members.

Four separate 1-hour-long focus group sessions were conducted, each led by two interviewers who were members participating in the Fountain House PAR initiative. Participant group size in each session ranged from two to five interviewees. The focus group procedure was developed by the participating member interviewers, who were trained on interviewing techniques for qualitative research studies. The focus group procedure was structured as an open discussion surrounding the following core questions (the first two chosen by members and the final chosen by the Fountain House Board):

1. How has your life changed since coming to Fountain House?
    a. How might your life be different now if you had never joined Fountain House?
2. How do you relate to staff at Fountain House?
    a. How do staff relate to you?

   b. How do grievances get handled?
   c. How do you find working side-by-side here different than other places?

3. What do you hope to get out of Fountain House?
   a. Do you see Fountain House more as a destination or as a stepping stone?
   b. Where would you like to be in 2 years?

Interviews were recorded on secure devices and were later transcribed by members of the research unit who did not serve as interviewers. After removing all identifying information, the transcripts were then analyzed by Fountain House members in the PAR working group, who identified salient themes and narratives that emerged in the interviews through the lens of shared lived experience.

2.3 Analysis

Analysis was conducted *via* two phases. The first phase involved identification of themes within transcripts that stood out due to the salient meanings attributed by participants or to the level of occurrence. Consensus coding was conducted for each transcript where at least three member researchers, supervised by a professional research staff, would review the data independently and then convene as a group to review and select agreed upon themes. After consensus coding was completed, each transcript was reduced to an agreed upon one-page narrative summary that wove the salient, essential themes together into a more general story. In the second phase, these four summaries and their identified themes and illustrative data were transformed into a singular narrative summary that captured the core meanings of themes. This stage featured quoting, combining, and paraphrasing data from separate focus group transcripts into a single coherent structure (Sells et al., 2004; Malterud, 2012). The following four thematic areas comprise this overall summary, as they were identified by the analytic team as the most salient from the data, with a particular eye toward transformative action and quality improvement potentials.

We offer a final note pertaining to how this study was informed by phenomenological research principles. To begin, the two main trainers of member researchers were phenomenologists, with the associated technical assistance following from that general positionality. In concrete terms, this meant that the data typically emphasized concrete examples and experiences; analyses typically focused on the meanings of experiences in community contexts; and the findings sought a degree generality thorough delineating core features that encompass members' experiences (Davidson, 2003; Wertz, 2005). Further, the study followed various established procedures for conducting phenomenological research, including the transmutation of lengthy raw transcripts into a one-page synthesis of essential major experienced meanings (Sells et al., 2004; Malterud, 2012). It should be noted, however, that the member researcher team developed their own innovative and hybrid approach to the above, infused by the member-driven and communal ethos of the clubhouse. As a prime example of this innovation, in the creation of one-page syntheses, the analysis group created a general story that incorporated *individual* focus group participant statements; however, when read as a whole, it provided a sense of a *community* experience, that is, of a community *experiencing*. In closing, we do not make claims to pure adherence to formalized phenomenological psychological methods, due in part to our extensive utilization of community-led methods. Yet, we do contend that the spirit of phenomenology—which was always supposed to be about the matters themselves or the "grassroots" (Spiegelberg, 1972, p. xlv)—has remained.

3 Results

Overall, study findings place emphasis on the theme of *action* in members' experiences—with respect to how action, agency, and valued activity were key components of meaning and recovery for people facing severe mental illness, and with respect to the key component of the research process itself (i.e., PAR). These higher order themes of action, meaningful activity, and the active pursuit of transformation of their lived spaces were threads that ran through the more specific findings of the project regarding members' temporal experiences of the clubhouse. By temporal experiences, we refer to their experience of life *before* the clubhouse, *during* the clubhouse, and *possible transformations of* the clubhouse, and clubhouse model, to better serve its members.

3.1 Driving research, dismantling stigmas, and creating new opportunities for marginalized groups

Member participants described various reasons for initially joining the PAR project, including the potential to be an active driver of research, to actively dismantle stigmas, and to create new opportunities for people facing marginalization and exclusion. Some members had a background in research, one of whom explained their participation by stating "I was very interested that mentally ill people could research mental illness ourselves. We are the focus of the research, so why not be the drivers of the research. I had a research background before my diagnosis, and so this served as an opportunity to get back into this world." Other members described wanting to be a part of the group because of its contribution in combating stigma, with one person stating: "I did not have any background in research, but I was interested in the class because I could develop my skills to become a researcher to help in the work of dismantling stigmas and create new opportunities for marginalized groups." However, some members' reasons for joining emphasized a more basic sense of being able to participate in a meaningful, productive, and generative activity, with one member stating: "There was no expectation for myself in coming to the class. It merely served as an activity for re-engagement, to do something, because I was feeling that I wasn't up to anything meaningful. All I knew is that I wanted to move on with something productive, to learn something."

3.2 I would rather be at the clubhouse. . . than be in the hospital

The contrast between life before and after entering Fountain House was vividly conveyed by interview participants. For many, becoming a part of the clubhouse was a major milestone in participants' lives. For them, it was a moment when the world opened up and "a new hope" came forth, filled with more meaningful activities and pursuits. Life before Fountain House often involved day-to-day struggles, a sense of purposelessness, depression, and isolation. As one person said, "[if I weren't here] I'd just be sitting around." The world outside the clubhouse presented all the challenges of unstable housing and prolonged unemployment, "running around on the streets," and encounters with harassment, law enforcement, and repeated hospitalizations. Social rejection could be extreme, from strangers who would "think I was carrying a knife 'cause I was mentally ill" to others who "might call the cops on [me]." Unlike these negative experiences in the outside world, participants described a welcome feeling of not having to explain themselves when coming to Fountain House as compared to everyday life previously. Respondents described relief from stigmatized interactions and relief at being accepted, even by themselves: "I've been able to accept what I am" and "I just feel very well liked and accepted here."

Though the pitfalls of the world outside the clubhouse looked different to different people, a common sentiment about Fountain House emerged, relating to it being a place of possibility. This sentiment often contrasted with their experiences of hospital settings: "I'd rather be at the clubhouse. . . than be in the hospital. . . coming here is going to help me to do things I want to do with my life." Members further described how their feeling of equal treatment and authenticity in member-staff relationships uniquely contributed to a feeling of egalitarianism and self-respect, "there are no doctors or therapists. . .members and staff are treated the same. . . like human beings." Indeed, some members spoke directly of Fountain House being a preferred alternative to conventional mental health day programs, describing other programs as hierarchical, "they called 'em clients there and they looked down on the clients. They considered them losers." Alternatively, Fountain House was described as a preferred place to find respite and strive toward goals: "I haven't been in the hospital in about 15 years," said one participant, "the more Fountain Houses we have, the more hospitals will go out of business."

In such terms, Fountain House was seen as a radical contrast to the stigma and social limitations they often faced as a person with severe mental illness: "It's an amazing place, there's no other like it in the world. . . we have people from different countries come all the time to find out our paradigm." It was a place where members could meet friends to see each day and a path toward stability in areas like housing and health care. Said one participant: "Years ago I didn't have many friends. I think I've come far now." Relationships with staff were described as purpose-driven, egalitarian, accepting, and humane by many of the members: "Everybody's equal here. No matter what the illness, what diagnosis, they treat you like a human being. . . treat me as important. . . I really feel as if I have something to offer." The person's world expanded from just oneself to a network of treasured relationships with peers and staff, working side-by-side each day, leading to a profound sense of belonging: "This is the place for me."

3.3 Needing more than just a place to go

Within the overall expression of belonging amongst members of Fountain House, there was also a sentiment about needing more than just a place to go, that meaningful opportunities were required for deeper fulfillment, beyond just being there. Some felt Fountain House fulfilled this desire, whereas others felt it came up short, particularly with regard to being able to provide opportunities for creative expression or impactful work. Initially positive experiences in the community could eventually wear off, with one member stating:

> *Fountain House gives me camaraderie and respite from some problems. However, I feel like I am not intellectually stimulated anymore. When I started at Fountain House everything was new and stimulating, and if I stayed home I would crash. For me it got me out of the house, but now I'm bored during the work-ordered day. It is a bit difficult for me to engage, and I feel like my creative self is not allowed to be expressed. Instead, I feel like I am being pressured to do busy work, I feel thwarted.*

Other members went as far as to describe some experiences in the work-ordered day as a "sheltered workshop." However, these same members went on to describe a scenario in which they were able to become engaged in an important task that arose when trees were knocked down in the backyard. Helping out on this task provided these same members with an opportunity to work collectively on a meaningful task to the benefit of the whole clubhouse, indicating that while certain work did not appeal to them, the clubhouse had other engaging opportunities for contribution. "There was a more worldly aspect to the task," one member elaborated, "unlike the tasks of making bookmarks and stuff, which can get monotonous."

Some members commented on experiences where they felt a need and desire for Fountain House to be more proactive with regards to overcoming and intervening in the persistent struggles many members face. As one member stated:

> *I have a tendency to be someplace and somehow get stuck there, like I'm in quicksand and I can't move out, so I wish Fountain House (FH) was more, that I was getting more assistance... I get ideas in my head and I can't put them into action, and sometimes I feel like the staff can't help me with that. I need help developing myself, more than just a place to come.*

Other members also spoke to this feeling, emphasizing that while they may not have as severe of needs as other members, their issues with mental health problems like depression still persisted and could go overlooked:

> *I'm not homeless, I'm not suicidal, but I still struggle with my depression... I feel like those members who have more needs get prioritized, while those of us who have had some success in the past are told that those resources are not for us... There's still room, especially for high functioning people, for improvement. I think we all want to be here for different reasons, but FH doesn't work perfectly. Depression can make it very difficult to follow through, so I'm just saying it's not just me personally but also my symptoms. The staff are also just not as available as I would like or the community needs.*

Many members spoke to the experience of staff unavailability, explicitly with regards to staff being taken out of the house by impromptu supported employment responsibilities known as transitional employment (TE), where staff must cover a position for an absent member, often rendering the former suddenly unavailable. As one member commented, "This TE thing that they have to respond to like that. She's on a TE, he's on a TE, she's on a TE, and it's just like by the time you get (to see the staff), you're frustrated." Other members spoke to this general frustration regarding staff having precarious schedules: "One is at the farm, one is in Alaska, and one is at diversity training. I could go up to 3 days without seeing my worker." This frustration with the precarious availability of staff and workers was also reported as an evolving circumstance that has changed over the long history of Fountain House:

> *When I first joined here, there wasn't as much to do but I felt there was more of an intimacy between staff and members. I feel like maybe there could be more one-on-one time. I feel like maybe Fountain House could try to take some of the good qualities of what it used to be like. I would meet staff out for lunch together or do different things and I don't feel that happens that much anymore, but I do feel that staff really care about their work, and they try to support me but they don't really do therapy. There was more one-on-one time back then. The staff and I built a rapport together. They knew how I was doing in all aspects of my life.*

3.4 I figured out how to navigate Fountain House, what it can give, and what it can not

Members' reports indicated the possibility of a dynamic recovery journey in their engagement with Fountain House, in that over time they navigated how to actively explore the supports within, manage the limitations of, and creatively contribute to the Fountain House community. As one participant described:

> *I've had success this time around because I've figured out how to navigate Fountain House, what Fountain House can give to me and what it can't, and where I need to go to seek out some other things and other sources of support. And again how I can better engage myself in this community so that I'm maximizing what I can bring to the community.*

Many participants echoed this agentic sentiment, speaking to their quest to be "proactive in (their) own health." Members spoke to this experience of the clubhouse as a community where one is accepted upon showing up, even though not quite knowing one's way, while subsequently engaged and invited toward finding a niche in the community.

Across other reports, it was also suggested that members had an evolving perspective on the role they saw Fountain House foreseeably playing in their life: as their own life goals and trajectory shifted, so did the nature of their relationship with the clubhouse community and setting. As one member stated regarding not needing the supports of Fountain House as much as they used to: "I wouldn't want to leave FH but I may engage with it differently." Another member elaborated on this point, stating:

> *It gives me structure even though I don't need Fountain House as much I did before... In this way, Fountain House is both a stepping stone and a destination for me... I feel like I've made some very strong relationships with members as well as staff working on those projects and it makes me feel like I can accomplish things...[but] I still need their ability to keep me congruent and on schedule... This is a place that I*

> *always want to volunteer and be able to come to, whether it's a Thursday night or a work-ordered day, I see it as a part of my life. . .for a long time.*

It appears that the development of supportive relationships and a reliable space of welcoming were key to what motivates and keeps people engaged with Fountain House: "I have a lot of friends who I met at Fountain House. Years ago, I didn't have many friends. I think I've come far now. . . I want to be more social. I want to achieve." One particular exchange between two members effectively highlights the experience of one's relationship with Fountain House evolving over time:

> *P.1: For me, for a long time, I felt like I wasn't getting anything out of it. I would leave for sure and [not] come back for years. In this go around, I feel like I made some very strong relationships. With peers as well as staff, and it's staff that has helped me to stay. In those relationships and talking to people in the last year I kind of figured out where I could be effective here in this community while using my skills in this community and I started to do that.*

> *P.2: But what about outside of Fountain House–I assume you want to stay. I mean you will always be a member of Fountain House but from what I heard from you, you don't want to be here in 20 years. So what about leaning in that direction with what you have you gotten from Fountain House?*

> *P.1: So it's a matter of the relationships I made here. . . [The staff are] so encouraging and supportive, and that has been helpful. To me in 20 years, do I want my work with Fountain House to look differently? Of course. I don't know if I want to leave the Fountain House community in 20 years. I think there's something valuable here for me in terms of breaking isolation. In terms of coming to a community where I don't have to explain things and that's important to me.*

Others described the persistence of Fountain House in their lives through various life events: "I haven't been in the hospital for 8 or 9 years I think, and I had a pretty good streak here the last 6 years. . . I graduated college. . . I worked. . . I feel like my mental health has improved a lot."

Though members' relationship to Fountain House continually evolved, they also described how it can become a lifelong fixture in their lives—changing in meaning and need but stable in presence. "I'd like to stay connected and I've been here for so long it's almost like a part of my life now and I feel like I'm kind of a lifetime member because I've been here for so long [since the late '80s right after high school] and I've come back. I've went away and left Fountain House and did my own thing and then I valued Fountain House enough to come back. . ." One member reported having integrated Fountain House into their life, and described it as, "a place that I always want to volunteer," as well as being a place they would always want to engage with. "I wouldn't leave the Fountain House community but I may engage with it differently whether or not I'm engaged with the community or working full time successfully." Another member was not sure where they would be in 2 years, but they could say that Fountain House would still be a part of their lives. It is a place that they always want to come to, "whether it's just a creative writing group Thursday night, or just being part of the work-ordered day. . . I see it as a place that is part of my life, and that is an important part of it."

4 Discussion

This PAR study, featuring the direct contribution of persons with mental illness in all aspects of the research process, sought to better understand and improve members' experience of everyday life in a prominent psychosocial clubhouse. The ensuing study findings emphasize the centrality of *action*, *agency*, and *meaningful activity* in the lives and recovery journeys of people with mental illness. In the focus groups, members reported experiencing the clubhouse as a space of possibility, hope, and belonging, which contrasted with their experience of inactivity, stigma, depression, and hopelessness prior to that point (Section 3.2 "I would rather be at the clubhouse. . . than be in the hospital"). Findings also portrayed members' need for, and pursuit of, *transformation* within the clubhouse space itself to provide more opportunities for meaningful work and staff engagement, rather than what they sometimes viewed, for instance, as merely busy-work (Section "3.3 Needing more than just a place to go"). In addition, findings showed how such a hospitable, non-hospital setting did not hold a uniform meaning across time for members with mental illness: meanings shifted relative to the specificities of their own *agentic* goals and life-historical trajectory (e.g., whether it was experienced as a stepping stone or a final destination) (Section "3.4 I figured out how to navigate Fountain House what it can give, and what it can' not"). Finally, although it was not formally studied in the current project, a general consensus of members who contributed as researchers in the study (some of whom are authors of the current manuscript) noted how direct participation in this project *as a PARer* afforded opportunities to actively combat stigma, to be a driver of research, and to engage in what they viewed as a generative activity (Section "3.1 Driving research, dismantling stigmas, and creating new opportunities for marginalized groups").

The portrait of action and activity illustrated above contrasts with those found in the history of psychology and psychiatry that have—either implicitly or explicitly—often placed more emphasis on passivity, for instance, that people living with mental health disorders are largely passive experiencers of symptoms and passive recipients of treatment. Variations of these themes have also been subtly repeated within the strands of phenomenological psychopathology that, in their descriptions of the (mostly internal) world of mental illness, have tended to lose sight of the person and their surrounding context, or, further, to describe these as largely passively experienced illnesses or as deviations from a more normative being-in-the-world (Davidson et al., 2004). However, such a phenomenological psychology, as Husserl (1954/1970, 1981) suggested, may unwittingly take for granted what appears as "person," "illness," and "world" rather than inquiring into their very constitution, including such surrounding notions as "normal" and "abnormal," "healthy" and "pathological." Further, such a world, rather than being defined merely by passive reception, is always actively being constituted on intersubjective grounds, albeit with the challenge posed by previously sedimented meanings. What this means is that the lived experiences of people with mental illness cannot be separated from the constitution of the world, inclusive of the norms, processes, prejudices, and possibilities therein, and of the active contestations of each (Davidson and Cosgrove, 2002; Davidson, 2003; Jenkins and Carpenter-Song, 2009). What this also means is that the current state of affairs may not be the only state of affairs as activity and action are possible, both individual and collective, including the activity of recovery, and the roles of persons, structures, and institutions within it. Discussion of such intersubjective processes being facilitated in clubhouse program settings has been explored in relation to positively impacting recovery trajectories in serious mental illness (Rice et al., 2020). One implication for the broader study of *mental* health and illness is to more closely interrogate the *social*, *institutional*, and *community* structures around the person, as potential contributors to illness and to recovery. Otherwise, the risk remains of locating the determinants of mental health, agency, and activity as solely inside the person, with psychology in danger of becoming a world unto itself, divorced from the real world, out there; the latter bias would be a variation of psychologism, the overcoming of which has always been a central aim of phenomenology (Desai, 2018; Davidson, 2021).

4.1 Practice and policy implications

This PAR project, staffed and infused with member energy and participation, examined the experience of Fountain House from members' perspectives. The goal was to produce actionable insights that could lead to community improvement. Part of the challenge of elucidating targets for intervention was that Fountain House was not experienced as a singular thing. It appeared differently to different members, and for any individual member, its function and role in their lives could change over time. The meaning of Fountain House as a place and communal space evolved with the lives of longtime and new members creating a constellation of needs and services that were dynamic to the constitution of the membership, regardless of whether the building and staff stayed the same. This was the first main implication of our findings, that the meaning and role of "Fountain House" may evolve over time for members, their relationships, interactions, and modes of giving and receiving. In some cases, it was even less of a place as such, but a stable presence in one's life that members carry with them and know they can return to in times of need.

Within the expansive range of what Fountain House could be in a person's life, members could come to experience the clubhouse as becoming a true home that meets their needs and desired roles, or, as one participant described, simply being the "place for me." Many members described their initial draw to Fountain House as being due to the clubhouse sense of community and engagement disrupting previously persistent experiences of loneliness and disenfranchisement, a finding consistent with other recent studies on the impact of community and the "oasis"-like qualities of the clubhouse model (e.g., Conrad-Garrisi and Pernice-Duca, 2013; Mandiberg and Edwards, 2013; Kinn et al., 2018; Tanaka et al., 2018; Desai et al., 2021). However, this was not the automatic or continual case for everyone. This was highlighted in the examples of some members experiencing frustration in having their needs met. Such experiences draw attention to possible revisions Fountain House may administratively and communally undergo for the sake of either meeting the evolving needs, or setting clearer expectations, of its dynamic membership. This focus on unmet needs coincides with our action-oriented framework intended toward identifying avenues of potentially beneficial change. We believe that one of the major sources of contribution of this project to the wider literature on clubhouses and psychosocial research is in being able to identify areas of improvement, in a respectful and yet constructive manner—insights that were greatly facilitated by the project being member-driven and member-to-member run. We break these aspects down into three main domains: boredom/stuckness; nature of work; and staff engagement.

The above evidence suggests that members can come to find that, while the initial period of engagement may be characterized by expansion, opening, and excitement, this momentum can slow down, bringing members to experience a sense of stuckness, boredom, or stifled creativity. This experience is directly tied to the nature and quality of the everyday work experience. Members found that there were important differences in the meaning and enjoyment of work, depending on the type of work, the background of the member, and the synergy between the two. Experiences varied in terms of how extensively a member perceived it as, for instance, drawing on their creative side or as impacting real concerns in the world. One member offered the quite provocative, critical description of coming to view the work-ordered day as creating a "sheltered workshop," which illustrates the range of members' varying views of this core clubhouse feature and its possible discontents. Greater attention by clubhouses to facilitating more meaningful and generative activities for these members—with direct member input—may be warranted. During the discussion of these findings with the study team, there was also consideration of the cultural implications of work, that is, whether the kinds of work available in the broader economic structure of the US, in general, may often contrast with the important clubhouse goals of developing relationship, community, and purpose.

Members also differ with respect to their experience of staff engagement. Members can come to want more engagement opportunities with staff, particularly when staff are often called away to other obligations. The clubhouse model requires a deliberate understaffing policy so that the clubhouse could not be maintained without the contributions of its members (Propst, 1992), but there may be cause for some reconsideration of this in light of members' feedback. However, previous research on member-staff relationship done by Pernice-Duca (2010) found that relationships with other members lead to greater improvements in mental health than receiving support from staff, for which the deliberate understaffing model of Fountain House may encourage member-to-member support. At the very least, the policy of deliberate understaffing could be better explained to members, which would improve transparency and potentially limit disappointment, or be supplemented by formally designating experienced peer-members as support staff. Such findings also bear comparison to previous research on the difference between clubhouse staff being more likely to describe the clubhouse community in terms of broad standards and values (Herman et al., 2005), whereas member perceptions focus more on staff-member relationships, program empowerment, and the importance of work (Burt et al., 1998).

There were several limitations of this research. First, while we attempted to produce qualitative themes about experiences of Fountain House, we do not claim that these themes capture all of the unmet needs that members may face. However, we do suggest that these themes are pertinent, given the contributions of the member-stakeholders themselves to the study. Additional research is required to further explore these and new, arising areas of concern, including specifying the full determinants of robust action and agency among community members. Second, as this was a qualitative study describing experiential themes, future research would need to determine the quantitative frequency of specific experiences described in this study, as well as the relation of specific themes to factors like membership length and other key demographics. Third, there may have been a selection bias toward members who were verbal and active, and against those who may not be as engaged in the clubhouse in general. Fourth, Fountain House is a large clubhouse program with a variety of support services and contexts; our findings and quality improvement suggestions should thus be viewed within the context of relatively small proportion of participants in relation to a large total membership and within the context of a large program like Fountain House (i.e., they may not be representative of member experiences in smaller clubhouse programs).

5 Conclusion

This paper demonstrates the unique contributions that can be developed by members in therapeutic communities conducting research on themselves for themselves. Such research not only helps provide insight into the experiences of mental health service beneficiaries, but also provides a concrete mechanism for those experiences to be represented in research methods, qualitative analysis, and program evaluation. The research being conducted by the community, for the community, directly benefits life at Fountain House by providing constructive feedback from the main beneficiaries of the clubhouse model, the members. It also provides an opportunity for member researchers to develop a research skillset that can be applied in the pursuit of future community interests and action.

Data availability statement

The datasets presented in this article are not readily available because they are qualitative in nature, and there is a need to preserve anonymity and confidentiality among participants and the organization. However, key data are presented directly in the text. Requests to access the datasets should be directed to KR, krice@fountainhouse.org.

Ethics statement

The studies involving human participants were reviewed and approved by the Fountain House IRB. The patients/participants provided their written informed consent to participate in this study.

Author contributions

Members of PARCO Group were members of the Fountain House Research Unit and community who contributed to the design, implementation, and analysis of the research project. All authors listed have made a substantial, direct, and intellectual contribution to the work, and approved it for publication.

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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

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Case report: Clinical lycanthropy in Huntington's disease

Nick Medford[1]* and Natasha Sigala[2]

[1]Department of Neuropsychiatry, South London and Maudsley NHS Foundation Trust, London, United Kingdom, [2]Department of Neuroscience, Brighton and Sussex Medical School, University of Sussex, Brighton, United Kingdom

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EDITED BY
Elizabeth Pienkos,
Clarkson University, United States

REVIEWED BY
Russell L. Margolis,
Johns Hopkins University, United States
Jasper Feyaerts,
Ghent University, Belgium

*CORRESPONDENCE
Nick Medford
✉ nick.medford@slam.nhs.uk

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We describe the case of a patient diagnosed with Huntington's disease (HD), who, following a two-year history of anxiety with obsessional preoccupations, developed psychosis with clinical lycanthropy: a prominent delusional idea that he was a werewolf. Although there was no benefit from various antidepressants and antipsychotics, there was remarkable improvement of his symptoms following prescription of Clozapine. His choreiform movement disorder also improved as his mental state settled. Although some reported cases of clinical lycanthropy are related to neurological conditions, this is the first case in a patient with HD. We also discuss the relevance of cultural and personal factors in the expression of a delusion that incorporates disgust, and the potential role of somatosensory aberrations and misidentification of self.

KEYWORDS

lycanthropy, Huntington's disease, delusions, psychosis, zoanthropy, werewolf, intermetamorphosis

1. Introduction and case description

A 63-year-old white British man with a diagnosis of Huntington's disease (HD) was admitted to an inpatient mental health unit, and transferred to the specialist inpatient neuropsychiatry unit 3 weeks later. He had an approximately 2-year history of anxiety with obsessional preoccupations, progressing to psychosis, and his condition had not improved despite various antidepressants and antipsychotics. On admission, he was in a state of near-constant mental and physical agitation, with prominent choreiform movements affecting his upper body, and repeatedly stated that he was becoming a werewolf. He was preoccupied with this and a range of other transgressive and apocalyptic ideas, stating that he had an urge to strangle his wife and eat her body, also to defecate in a church, and that God had died (despite also saying he did not believe in God). He had not acted on these ideas apart from one occasion prior to admission when he had placed his hands around his wife's neck, but had not exerted any pressure; his wife stated that she did not feel in danger during this incident.

Psychological difficulties began about 2 years prior to this admission. At that time, he was living in France, and had become increasingly anxious, developing what his wife described as "mood swings", becoming unusually irritable at times, interspersed with periods of low mood. He was prescribed Paroxetine which initially appeared to be helpful. About a year after this, he again became anxious and began to develop unusual preoccupations (for example, around feces) as well as a compulsion to strangle his wife. He was prescribed Olanzapine which was gradually increased over several weeks to a dose of 20 mg per day, but his wife reported that his mental state and sleep continued to worsen, and he was admitted to a psychiatric unit in France for 1 week. In addition to the above symptoms, at this time he was also describing odd electric-shock type sensations which moved from the left side of his head to his left arm 'as if my body was freezing'. His symptoms continued to worsen and after another 2 months he had a further 4-week psychiatric admission, now saying he had the sense that he was an animal, which then developed into the idea that he was turning into a werewolf. His preoccupations with feces and strangulation intensified around this time. In France he was prescribed typical antipsychotics (Loxapine and later Cyamemazine), in combination with Olanzapine. His wife did not think this was beneficial. Mianserin was also commenced which was reported to have helped with sleep, while he was recorded as having had a paradoxical reaction to benzodiazepines, which were avoided thereafter. Some of the drugs prescribed in France reflect differences in treatment approaches, as these are only rarely prescribed in the UK.

He and his wife subsequently returned to the UK. His agitation, and the intensity of his obsessional preoccupations, and belief that he was becoming a werewolf, increased, leading to an emergency admission as above, initially to a general adult psychiatry ward, with transfer to a specialist neuropsychiatry unit after 3 weeks.

Background history was that his mother had been diagnosed with HD when she was 50, and had died at the age of 60. He recounted distressing memories from his teenage years of his mother being in a state of aggressive agitation. He himself received his HD diagnosis at the age of 58, following genetic testing while he was asymptomatic, thinking it would prove that he was not a carrier. This genetic testing revealed a 41 CAG repeat. He did not smoke, or use illicit substances, and drank alcohol only occasionally. This presentation was his first contact with psychiatric services in the UK.

2. Diagnostic assessment and therapeutic interventions

At the time of this admission he was not on any antipsychotic medication, but was started on Quetiapine, and at the time of transfer to the specialist neuropsychiatry unit his prescription was slow-release Quetiapine 200 mg per day, Mianserin 10 mg at night, plus Promethazine 25 mg as required for agitation, and Lactulose and Sodium Docusate as required for constipation. His belief that he had become a werewolf was expressed frequently and he would look in a mirror and state that his physical appearance had changed. At this point he was also preoccupied with his bowel function, stating repeatedly that he was "completely blocked", and that this was somehow connected with the death of God and the imminent end of the universe. He also stated that he was the Devil, that he was physically changing and shrinking, and that he believed he would die soon because his internal organs were becoming exposed. He was able to acknowledge that these ideas did not hang together, and felt unable to explain this, even to himself. On initial physical examination he had prominent choreiform movements of his upper body, but normal tone, power, sensation and brisk reflexes. Cognitive examination was challenging as his level of agitation made it hard for him to engage with testing, but no gross cognitive deficits were identified. He was however apparently unaware of his choreiform movements. A structural MRI brain scan showed unusually small caudate nuclei and widening of the lateral ventricles, consistent with a diagnosis of HD (Figure 1).

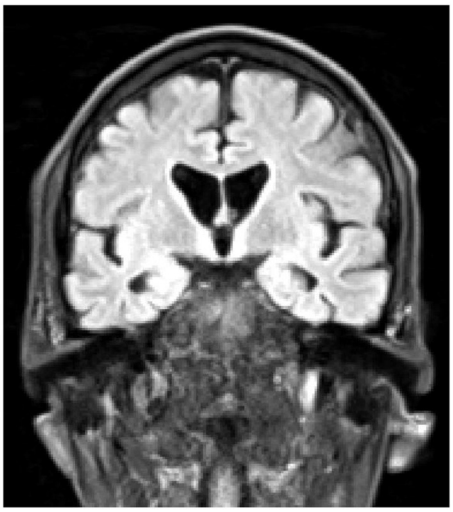

FIGURE 1
Coronal T1-weighted MRI scan, demonstrating atrophy of the caudate nuclei, and enlargement of the lateral ventricles.

Early in his admission to the neuropsychiatry unit, there were a few occasions when he lunged at members of staff with his hands poised to take hold of their necks, but would pull away before making contact and apologize. His agitation and outbursts of aggression necessitated 1:1 nursing and detention under the Mental Health Act, as he was felt to be a risk to others. His medication compliance was variable, and there was no evidence of improvement when taking Quetiapine despite this medication being increased to 300 mg bd and prescribed at this dose for a further 4 weeks. A decision was made to switch to Clozapine and this was slowly titrated to a dose of 450 mg per day in divided doses. Initially the necessary blood monitoring was very challenging as he would refuse blood tests, saying that the needle was larger than his arm, or that there was no blood in his veins, or that there was no point sending his blood for analysis as he no longer had human blood. It was necessary for medical staff to spend considerable time calming and reassuring him before he would agree to blood tests. As the dose of Clozapine was increased and his mental state improved, this became more straightforward.

Soon after the introduction of Clozapine he became more settled and it became easier to engage him in conversation and ward activities. It was felt that there was a depressive element to his psychosis, as evidenced by nihilistic delusions, and Mianserin was switched to Citalopram, initially 10 mg per day, increasing to 20 mg per day after 1 week.

There were some adverse effects of Clozapine, with an initial worsening of his constipation necessitating an increase in laxative use, and hypersalivation, which fortunately settled without the need for specific treatment.

Over the following weeks, his mental state improved as Clozapine was slowly up-titrated. His unusual ideas and beliefs became less prominent or disappeared altogether. He was no longer agitated or aggressive, and was euthymic, largely free of anxiety, and able to reflect on his experiences. The Mental Health Act detention was rescinded, with him remaining on the ward as a voluntary patient. A period of trial leave from the ward, staying with his wife, went well with no concerns raised, and he was discharged soon after. Notably, as he improved, his movement disorder also became much less prominent, and by the time of discharge this was only evident as occasional subtle involuntary jerks of his upper body. At this stage he was able to engage more fully in formal cognitive testing, which demonstrated above average IQ with no evidence of cognitive deficit.

Approximately 4 years following discharge, he is on no psychotropic medication but remains relatively well, with no recurrence of psychotic symptoms and only mild movement disorder, consistent with his genetic testing, which would suggest he will be relatively mildly affected by HD. He is living independently with his wife and is able to self-manage all activities of daily living, and pursue his interest in gardening.

3. Discussion

Huntington's disease (HD) is an inherited genetic progressive neurodegenerative disease with cognitive, motor and psychiatric symptoms, caused by a mutant protein, huntingtin, which results from an unstable expanded trinucleotide CAG repeat on chromosome 4. In the normal population the CAG repeat length ranges from 10 to 35, whereas in patients with HD it ranges from 36 to 121, with complete penetrance occurring from 39 repeats (1), the number of repeats being negatively correlated with the age of onset of HD (2), and positively correlated with rate of caudate atrophy (3). At protein synthesis, these abnormal CAG repeats result in a polyglutamine chain being incorporated into the huntingtin protein, producing a mutant form which accumulates in cells and is neurotoxic. The medium spiny neurons of the striatum are particularly susceptible, and atrophy of the caudate nuclei is the characteristic radiological finding (1).

Clinically, HD is characterized by the triad of the typical movement disorder, subcortical dementia, and a positive family history, with onset of overt symptoms usually occurring in the fourth or fifth decade. Psychosis occurs in 3–11% of patients with HD (4), usually as a relatively late manifestation. The decision to use Clozapine, despite this being an off-license indication, was based on the fact that multiple antipsychotic medications had already been tried without benefit, and there are published cases in which treatment-resistant psychosis in HD responded to Clozapine (5–7). In the last two of these case reports, the authors note that good response to Clozapine was seen only at doses of 425 mg and 450 mg per day respectively, higher doses than those used in earlier reports (7). This latter (450 mg per day) is the same dose on which our patient was stabilized, although in our case a gradual improvement in mental state was noted throughout the up-titration. There is also evidence that Clozapine may have a role in ameliorating the movement disorder of HD (8), although an open-label trial suggested these benefits are modest at best (9).

It is now well recognized that subtle cognitive, emotional, and behavioral changes often predate the onset of other symptoms of HD, sometimes by decades (1). Commonly these changes are irritability, cognitive rigidity and stubbornness, depression and anxiety with obsessional preoccupations, and apathy (10). These features may be severe enough to attract a diagnosis of organic personality disorder. In our case, there was evidence of these features (aside from apathy) being present for at least 2 years prior to the development of frank psychosis. The psychosis itself was poorly systematized, as is commonly observed in HD-associated psychosis, with a range of ideas and beliefs that did not hang together, unlike the elaborate delusional systems frequently encountered in schizophreniform illness. In these respects, this case illustrates some quite typical features of mental and behavioral changes associated with HD. The highly unusual feature of our case is clinical lycanthropy: the patient's belief that he was transforming into a werewolf.

While clinical lycanthropy (the delusion of transformation into a wolf, from Greek lykos, "wolf" and anthropos, "human") is rare, the wider cultural idea of the werewolf has an extensive legendary and literary history, e.g. (11–13). The Ancient Greeks worshiped Zeus Lycaeus, who transformed Lycaon, the cruel King of Arcadia (a region plagued by wolves) as punishment for serving the god a dinner of human flesh, according to Ovid's Metamorphoses, Book I (14). In Ancient Egypt, Anubis, the god of Death and the Underworld has the head of a jackal, which is an African golden wolf (15). Anubis is also represented with the lunar disk, as a symbol of resurrection and rebirth (16), a theme repeated in the Byzantine iconography of St Cristopher (17), potentially referring to an ancient association of werewolves with the moon (15). The werewolves of antiquity symbolized moral shortcomings, while later accounts in Scripture implied the interference of satanic forces in human affairs (13). During the Inquisition, reports of werewolves reached 'moral panic' proportions: 30,000 were supposedly recorded in France alone between 1520 and 1630 (18). Why the idea of the werewolf should have recurred across so many cultures and eras is an intriguing question. A creature that is part-human, part-wolf can readily be seen as symbolizing the struggle between the civilized aspect of the human, with the accompanying obligations to observe social norms, and the animalistic, instinctual aspect, which chafes against such restrictions. A frequent feature of werewolf stories is that full transformation into wolf form is associated with frenzied violence and sexual activity, followed by guilt and self-loathing once a human form is regained. These themes may have explanatory power when it comes to cases of werewolf delusions: clinical lycanthropy. Fahy (12) summarizes case studies of clinical lycanthropy from the nineteenth and twenteeth centuries as compatible with patients' ≪ perception of themselves as evil, disgusting or guilty ≫, and argues that the powerful and evocative image of a werewolf's aggressive, cannibalistic qualities can be related to delusions characterized by guilt, sinfulness and disgust (12). Delusions are influenced by culture (19, 20), types of family relationships, and concepts of the self (15, 21, 22). We explore the relevance of these factors to our case further below. It has been suggested that lycanthropy is best classified as a Delusional Misidentification Syndrome (DMS), involving a global misidentification of self (23, 24). Another idea, discussed further below, considers lycanthropy as a form of cenesthopathy (pathological bodily sensation), developing as a result of somatic hallucinations and somatosensory aberrations (24, 25). About 24 cases of clinical lycanthropy have been reported in the medical literature between 1852 and 2020 (15); this case report is the first for a patient with HD.

To understand why this patient should have developed this particular delusion, and some of the other unusual ideas he expressed, it is necessary to move beyond descriptive labels such as "psychosis" and consider the phenomenology in the light of his subjective experience and the ideas outlined above. Although he was apparently unaware of his movement disorder, he nevertheless described strange and unpleasant physical sensations, a common experience in HD, and expressed a range of delusional ideas relating to bodily changes. In addition, he stated he had always had a horror of developing HD, in part because of painful memories of his mother's psychological deterioration during his childhood. He had reached the age of 58, apparently asymptomatic, when he underwent genetic testing to confirm to himself that he did not carry the HD gene, and was shocked to find that he did. It seems plausible that his sense that he was turning into a werewolf – something fiendish, monstrous – was rooted in this terror of the disease, coupled with some distorted perceptions of the bodily changes linked to the disease process. Some of his other symptoms, such as his sense that he was shrinking, or his apparently perceiving a hypodermic needle as larger than his arm, further support the idea that sensory misperceptions were a key element in the development of symptoms. Here the idea of "secondary clinical lycanthropy" (25) is relevant – the notion that lycanthropic delusions can arise from somatic hallucinations and/or alterations in the sense of physical identity in people with psychotic illnesses, principally schizophrenia. In our patient, there were actual, not merely hallucinatory, changes in his physical state, and a knowledge that he had a serious progressive disease of which he had a particular horror. The caudate nuclei (atrophied in this patient) are part of the striatum, which, among other functions, regulates feelings of reward, pleasure, and aversion to negative stimuli e.g. (26), as well as disgust processing, including moral violations (27, 28). Abnormal perception of disgust, as well as self-related disgust, has been specifically suggested as a contributing element in the development of clinical lycanthropy (29). This combination of factors, all readily applicable to our case, would seem to provide fertile ground for the development of clinical lycanthropy, based on misattribution of bodily sensations and a fear of becoming unwell, negatively altered, and socially unacceptable through the progression of HD.

The consideration of phenomenology, and of the meaning of symptoms, should always be at the heart of any attempt to understand and formulate psychiatric presentations, but it is all too easy for this principle to be abandoned in the context of organic conditions such as HD, where the presence of well-established genetic and biochemical abnormalities may seem to provide sufficient explanation for symptoms. However, knowledge of the biomedical basis of disease should not discourage a psychodynamic approach – rather these two types of knowledge should be complementary. In this case, while the underlying diagnosis of HD was already known, understanding the content of the patient's psychosis depends on a psychological formulation based on the patient's particular life history and subjective experience. This blending of scientific knowledge with phenomenological insight is the essence of neuropsychiatric formulation and practice.

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.

Ethics statement

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

NM oversaw the clinical care of the patient and prepared the case description. NS made important conceptual contributions and added theoretical material to the Discussion section. Both 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

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Psychotic disorders of space and time – A contribution of Erwin W. Straus

Marcin Moskalewicz[1,2,3]* and Thomas Fuchs[1]

[1]Phenomenological Psychopathology and Psychotherapy, Psychiatric Clinic, University of Heidelberg, Heidelberg, Germany, [2]Philosophy of Mental Health Unit, Department of Social Sciences and the Humanities, Poznan University of Medical Sciences, Poznań, Poland, [3]Department of Ontology and Epistemology, Institute of Philosophy, Marie Curie-Sklodowska University, Lublin, Poland

This paper presents and discusses a manuscript by one of the core founders of phenomenological psychopathology, Erwin W. Straus, concerning psychotic disorders of space and time (see attached Supplementary material). Written in June 1946, the manuscript is published for the first time as supplementary material to this paper. It is a clinical case-study of a patient with psychotic depression from Henry Phipps Clinic. It contains themes known from both Straus' earlier and later work on lived time and mental illness, in particular a critique of physicalism in psychology, a vindication of primary sensing, a description of the spatiotemporal unity of lived experience, and the notion of temporal becoming. However, it is the only work by Straus that explores in such detail a patient's case and shows how the lived experience is spatiotemporally structured and intrinsically related to affectivity, embodiment, and action. The manuscript is yet another piece of evidence of Straus' significance in developing the field of phenomenological psychiatry in both Germany and the United States.

KEYWORDS

lived time, lived experience, depression, psychosis, phenomenology, temporal delusion, physiognomy, psychopathology

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EDITED BY
Elizabeth Pienkos,
Clarkson University,
United States

REVIEWED BY
Paolo Azzone,
ASST Rhodense,
Italy
Sérgio Saraiva,
Centro Hospitalar Psiquiátrico de Lisboa,
Portugal

*CORRESPONDENCE
Marcin Moskalewicz
✉ moskalewicz@gmail.com

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Introduction: the manuscript and its author

This paper presents and discusses an unpublished manuscript by Erwin W. Straus titled "Psychotic Disorders of Space and Time" from 1946 (see attached Supplementary material) (1). Completed on a Sunday afternoon in June 1946, but certainly conceived earlier, the 58 typewritten pages long set of reflections oscillates around a clinical study of a patient with psychotic depression from Henry Phipps Clinic, where Straus was researching compulsive behaviors in the 1940s. It is a detailed exploration of a troubled subjectivity that shows a direct application and relevance of phenomenological categories for understanding and possibly treatment of depression. The descriptions of the patient's unusual lived experience are woven into Straus' more philosophical reflections concerning mostly the nature of normally lived space and time and his critique of physicalism in psychology in particular.

Erwin W. Straus belonged to the group of core founders of phenomenological psychopathology. A native of Germany, Straus studied medicine in Berlin and Munich, and begun his scientific carrier by defending a medical doctorate in 1919. He specialized in psychiatry under Karl Bonhoeffer and neurology under Richard Cassirer (2–4). Alongside luminaries, including Ludwig Binswanger, Viktor Emil von Gebsattel, and Jürg Zutt, he established the first and leading phenomenological psychiatry journal in Europe – Der Nervenarzt.

Straus has been concerned with the question of time since the very beginning of his career. In an early 1926 paper *On Individuality*, in the context of understanding biological and psychological theories of human development, he observed that: "Everything depends upon how time is conceived. We need a theory of time, which makes it possible to transform the mere succession of a temporal series into a relationship immanent to the things" (5). In another early article on depression from 1928, Straus suggested that distortions of the temporal structure of experience may be able to provide ground for uniting otherwise separated categories of mental disorders (6).

In 1938 Straus began his forced emigration to the United States, initially as a professor of psychology at Black-Mountain College in North Carolina (1938–1944), and then as a research fellow at John Hopkins University (1944–1946), where he worked on the *Psychotic Disorders of Space and Time* manuscript. Why the manuscript was never published remains unclear. One explanation might be that Straus never published patients' case studies –and both *Psychotic Disorders of Space and Time* from 1946 and *Temporal Horizons* from 1952 (published in 2018) (7) are thematized around clinical cases. Another reason could be that both unpublished manuscripts contain a lot of philosophical ruminations that Straus considered unfinished. In both, Straus develops his original conceptual framework to address the lived experience of space and time by disputing the views of important intellectual figures, Hume and James in the 1946 paper, and Bergson and Freud in the 1952 paper. Also, many of the threads from the 1946 manuscript can be found in other works by Straus: the theme of future orientation of experience was already explored earlier (6), the thoughts on physiognomy appeared in Straus' book *On Obsession* (8), some theoretical thoughts on time in his later *Chronognosy and Chronopathy* paper (9), and the patient's depressive psychotic experiences were quite probably used in *Disorders of Personal Time in Depressive States* published a year later. Also, in 1946, Straus got a new job as a Director of Research and Education at the Veterans Administration Hospital in Lexington, Kentucky (1946–1961) as well as a Lecturer at the University of Kentucky (1946–1956). In Lexington, Straus kept working on the issue of lived time, on which he published three more papers (9–11). Neither of those, however, nor any of his unpublished works on this subject compares with the scope and comprehensiveness of the *Psychotic Disorders of Space and Time.* Straus traveled back to Germany several times but remained in Lexington, where he died in 1975.

Spatio-temporal unity and disunity in psychopathology

At first sight, Straus' patient, whose experiences are discussed in the manuscript, has a practical problem with lived space – he easily gets lost in a city that he nevertheless knows well. Simultaneously, he has some odd perceptual and illusion-like experiences regarding space. For example, some things appear to him as flat and remote, and others as big. A ball thrown seems to move in slow motion, and the ward clock is seen as no longer round. The patients' symptoms are obvious to notice, but their underlying structure is hidden, as it were. These perceptual spatial problems, Straus argues, stem from more elementary and preconscious disturbance of space–time. The most explicit manifestation of this disturbance regarding time is the patient's statement that time ceased to exist. But what does that actually mean?

Straus begins his reflections by explicitly departing from the intellectual tradition of psychology, which, in his view, is tainted with some hereditary deficiencies. The major one is the reduction of the lived experience of space and time to perception –a recurrent theme of Straus' work despite his neuropsychiatric background. Perception of time has been traditionally addressed by chronometrical tasks, i.e., by exclusively conceiving it as abstract and ignoring more complex and hidden aspects of lived experience. Time cannot be an object of perception, Straus claims, for every perception has a temporal content. This temporal content is also not simply experiential but personal –it is related to one's life history and values and meanings. For example, Straus asserts that it is the meaning of impressions in the context of personal becoming that makes time pass slowly or fast in perception. Emotions are also temporal to the extent that temporality and affects are two sides of the same coin. Characteristically, Straus frames this issue in biological terms of the spectrum of lived future possibilities extending between survival and annihilation, and their corresponding emotional states.

Already in his early book *Geschehnis und Erlebnis* (Event and Experience) from 1930, Straus asserted that lived time is a central problem of theoretical psychology (12). He criticized all psychological theories (including psychoanalysis) that assume a notion of time presupposed by psychophysiology and psychosomatics, which leads one astray –away from the phenomena and toward a limiting physicalist notion. Overall, in his early theory of lived time, Straus presented a view of the human being as capable of escaping the natural causality and tragic fatalism of the past (13). In the 1946 manuscript, Straus goes back to what he sees as the philosophical underpinnings of the "original sin" of psychology in the work of Hume and James, whom he reproaches for their alleged cinematic view of temporal experience. Regarding James, this comes as a surprise given that James famously wrote about the specious present. Straus argues, however, that James' silent theoretical presupposition was psychological atomism that entailed a discontinuity of mental life. James allegedly could not free himself from the power of spatial motions and turned back to Hume's view of time as based upon a sequence of impressions. Straus, like Husserl before him, uses the example of a melody to show that impression of a sequence is prior to the sequence of impressions. The same concerns space, as spatial experience is not constituted on the basis of summing some perceptual parts together. Any such addition presupposes a spatial whole as a frame of reference. On the other hand, drawing a representation of space, such as a map, is distinct from its lived experience. It requires dislocating oneself from the center and looking at the world from a detached perspective.

The curious thing about the patient's delusion concerning the existence of time and his perceptual disturbance of space is that he claims that time has no beginning and no end for him, and that space is heavily deformed while actually *knowing* world time, *being aware* of the order of day and night, and *being capable* of symbolically orienting himself on a map. The patient thus loses the spatiotemporal perspective of lived experience (sensing), but not its abstract (numerical or geometric) representation (knowing). Unlike in aphasia, mentioned by Straus at the beginning, it is concrete and lived, and not abstract and schematic space that is primarily affected. Such split between sensing and knowing is a crucial psychopathological characteristics of the patient's lived experience. Regarding time, it has been compared to schizophrenic double book-keeping (14). Straus' patient presents such a split regarding both time and space, but it is temporality that appears as an underlying source of the disorder.

Straus saw these two aspects of lived temporality –which he called the immanent (or personal) time and the world (or clock) time –as originally intrinsically connected and not in ontological conflict (for more details on Straus' unity view of time and different stages of his thinking on this subject see (15)).

In his later manuscript *Temporal horizons* (1952), Straus exemplified his unity view with the concept of "today" as pertaining to both orders of time, binding them together, as it were (7). In a reflective attitude toward time, there is always some degree of discordance and asynchrony between these two aspects, but in pathological situations this discordance intensifies. Such discordance, Straus claimed, is based on the cessation of advancing toward the future, which concerns the whole of personal becoming, and not just the conative dynamics. In the extreme state of depressive psychosis, the lived time comes to a standstill. It is experienced as unreal, even though one can still perceive the movement of the hands of the clock and count the passing days on the calendar. The two orders or time are now wholly incongruent.

Straus will repeat his ideas on the discordance between personal and objective time from the 1946 manuscript in a condensed version in his *Disorders of personal time in depressive states* published shortly after (16). The same core conception will pertain to Straus' ideas on compulsive behaviors, though he will articulate the temporal discordance slightly differently. In his 1948 book *On Obsession* –the first published after moving to the United States – Straus explores obsession as a disturbance of sympathetic relation to the world (8). From a temporal angle, compulsivity consists of perfectionist expectations. While in daily life one typically leaves some room for the unknown, an obsessive person expects full certainty and thus has trouble dealing with the unpredictable. Trying to bring everything under control, one loses the continuity of life and experiences a sequence of present moments instead, as if living through the cinematic conception of temporal consciousness.

Critical considerations on the I-world relationship

In the *Psychotic Disorders of Space and Time,* Straus frames the theme issue in terms of the changes in the primary structure of the I-world relations that are affected not only temporarily, but also spatially – a continuous theme he will also explore in his later piece *Norm and Pathology of I-World relations* (17). In the unpublished manuscript, Straus re-defines Koffka's notion of physiognomic characters, which he grounds in the spatio-temporal structure of the "I-world relationship." Straus' departure point is phenomenological, but it is not focused solely on consciousness or being-there as intrinsically connected with the world. Unlike Martin Heidegger's concept of Dasein's being-in-the-world (18), Straus' notion is about the most concrete, embodied, and animal existence (17). A trained neurologist, Straus, different from Heidegger, emphasizes the continuity between self and nature. Still, like Heidegger, he performs a devastating, life-world-based phenomenological critique of the Cartesian, objective psychology as falsely following the principles of a mechanistic (linear and causal-effective) account of time. Such psychology, Straus argues, considers consciousness as a thing among things in the world, moving in a body through geometrical space and clock time, and neglects its most concrete and lived, even if directly non-observable content.

In his 1946 comments on the physiognomic characters, Straus vehemently opposes any purely physicalist analogies that would lead to losing sight of the phenomena themselves. He argues that sensory experience and power relations in the environment are indivisible – an example of his patient's deformed sense of the size of his physician. Physiognomic characters resemble in some aspects James Gibson's later affordances (coined in the 1960s), but they are more basic and have an affective, atmospheric, not only sensorimotor character (e.g., the "obtrusiveness of smells" which Straus mentions on p. 16 as a "physiognomic phenomenon"). Straus sees physiognomies as embedded in the primary structure of I-world relationship, in which the potentiality of movement and power are always involved.

In the manuscript, Straus also mentions *conation* or organic drive – the fact that experiencing beings are ahead of themselves and see the world in terms of capabilities, attraction, and repulsion, so that perception and movement are two sides of the same coin, as contemporary neurophenomenology also underscores (19). Sensory experience thus appears intrinsically connected with mobility, which is why the patient also finds it difficult to dance. One prereflectively responds to physiognomies as appealing or appalling, and the loss of conation means a loss of potentialities for action. Mental illness thus deforms the patient's lived space, inhibiting his responsivity and exchange with the environment (20).

These themes touched upon in the manuscript emerge from his earlier major work *Vom Sinn der Sinne* (published in English as *The Primary World of the Senses*), which presented the summary of his views on the anthropological foundations of psychology (21). The book was concerned with man's pre-reflective attunement with the world and vindicating sensory experience in its pre-cognitive right. Accordingly, Straus' concept of physiognomy points to the basal features of embodied experience and precedes much later discussion of situated enactive cognition, e.g., any experience is lived as attractive or threatening, supportive or resisting, to mention some of these features. The world is not faceless, and time and space are not abstract but lived and implicitly connected.

On this background, the basic alteration of physiognomic experience in psychosis can even undermine the sensorimotor affordance structure of the environment. As Straus points out:

> *"With the physiognomic dismemberment of space, performance and perception of motion change accordingly. In a baseball game A. Br. was not able to aim correctly at a goal When he looked at a ball in light, he had an impression of discontinuity comparable to that of, slow motion '" (p. 17).*

The reason for this lies in the fact that the structure of the experienced space is primarily not geometric-euclidean in nature, but dependent on the physiognomies of the environment as well as on the temporality of the experience: "Space, visible space, unfolds itself and is open to the future. Space is not a timeless order of places side by side; it is a field of potential action" (p. 17). Hence, if conation as the basis of the flow of subjective time comes to a standstill, then not only the future as a sphere of potential action closes off. Space also distances itself, and things move to an unreachable distance:

> *"The 'There' is experienced in disconnected remoteness. The patients cannot reach beyond themselves; they cannot anticipate a goal" (p. 17).*

Similar observations on the spatiality of endogenous-depressed patients have also been published 10 years later by

Tellenbach (22). The perception of spatial depth as accessibility is lost; space becomes featureless, flat, and distant. The psychotic disorders Straus examines by means of his case study thus prove the *primary unity of conation, temporality, and spatiality* in human experience.

An existential disorder?

Straus' identification of the patient's hidden spatio-temporal disturbance is based on his broader view of vital temporal becoming. The notion of disordered temporal becoming provides Straus with a diagnostic criterion that enables distinguishing endogenic depression from more psychogenic disorders. The criterion is whether the lived time is growing or declining, or immobile. From a critical angle, temporal growth and decline metaphors are spatial and binary, and they lack specificity. Straus speaks mostly of endogenic depression, but he also mentions the same syndrome of cessation of temporal becoming (which he calls, following Minkowski, *trouble générateur*) as pertaining to sexual neuroses and addictions. For example, Straus' depressive patient lives in a continuous present, in which time flows amorphously, not unlike in addiction (23, 24).

The distinction Straus draws is between those mental disturbances, which are more neurotic, and in which future potentialities are preserved (even though their actualization is suspended), and those, in which the very potentiality is afflicted (as in the case of the psychotic depressive patient). In the latter case, a vital inhibition is claimed to stem from the very core of organic becoming. Straus tacitly argues here against psychodynamic theories of depression and in favor of his biologically grounded phenomenology. Hence, he underlines that some alterations of temporal becoming may be of biological origin but still affect interpersonal relations and conflict situations. The process of temporal becoming is vital, implying that lived time is biologically grounded. However, as Straus will explain in his last published paper on time from 1967, it is also always mediated by personal experience (11).

Conclusion

The disorders of space and time are no longer rarely discussed in psychiatric literature, as Straus noticed in 1946. Almost 80 years later, they are a subject of considerable importance for phenomenological psychopathology (25). On the occasion of Straus' 70th birthday, Jürg Zutt wrote that the significance of Straus' distinctive thinking about central problems of clinical psychiatry would be appreciated only in the future. It is a view with which we –commenting on his unpublished work from over seven decades ago –utterly agree (26).

There are many parallels between Straus' and Minkowski's, as well as Binswanger's and von Gebsattel's reflections on temporal experience in mental disorders, even if expressed in different terminologies. These similarities have already been attributed to the subject's nature and commented upon (27). One of the key distinct aspects of Straus' thinking is that he overcomes Jaspers' restriction of phenomenology to pure descriptions and moves toward exploring the fundamental structures of lived existence. At the same time, unlike Ludwig Binswanger and Medard Boss, he does not succumb to Heidegger's fundamental ontology and, unlike Minkowski, to Bergson's metaphysics. Straus thinks for himself, and his analyses are always 'sober' and conceptually clear. At his time, he was perhaps a phenomenological psychopathologist to think in the most 'medical' way.

The unpublished 1946 manuscript is an evidence of this. What makes it unique is that, to the best of our knowledge, it is the only work by Straus that explores a patient's case in such detail, and on its basis shows how the lived experience is spatiotemporally structured and intrinsically related to affectivity, embodiment, and action. In today's 5E idiom, one would say that experience is 'emotionally enacted'. Straus' understanding of psychotic depression as an alternation of temporality and embodiment and their interpersonal embeddedness is thus very modern in its core, although not fully developed (28). The emphasis on physiognomy as underlying primary spatial experience and the variability of appearances though activity and movement is also original. Overall, Straus' significance for developing the field of phenomenological psychiatry in both Germany and the United States is indisputable.

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

MM transcribed and edited the Erwin W. Straus' manuscript and wrote the first draft of the article. TF corrected and amended the article. 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.2023.1150005/full#supplementary-material

SUPPLEMENTARY DATASHEET 1
Erwin. W. Straus, Psychothic disorders of space and time.

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