

Being at Home: A Feminist Phenomenology of Disorientation in Illness

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This article explores the relation among illness, home, and belonging. Through a feminist phenomenological framework, I describe the disorientations of being diagnosed with borderline personality disorder (BPD) and living with mental illness. This research anticipates the consequences of illness and serious (bodily) disorientations for a conception of belonging as seamless body–world compatibility. Instead, this article examines how the (in)stability of bodily dwellings in experiences of disorientation can suggest ways of being in the world that are more attentive to interdependency, unpredictability, and change in human experience. I argue that these types of dwellings function as a more capacious and apposite metaphor to account for variations in belonging. This discussion outlines the ethical importance of building worlds that make room for different ways of being at home in and through our interactions with others. Although my discussion does not supply norms for ethical action, I contend that a feminist phenomenology of illness generates saliences and illuminates sensibilities that can transform our ways of being with others.

To find a home in my body is to tell a story that doesn't exist.

Sick, Porochista Khakpour

In recent years, a rich body of work has brought to light the significance of phenomenology's focus on first-person descriptive accounts of embodied experience for the study of such diverse phenomena as pain (Svenaeus 2015; Kusch and Ratcliffe 2018), psychopathology and illness (Carel 2007 Ratcliffe 2015; Carel 2016a; Ratcliffe 2018; Fernandez forthcoming-a), phobic disorders (Jacobson 2004), sexed embodiment and sexual difference (Heinämaa 2010; Zeiler and Guntram 2014), disability (Diedrich 2001; Salamon 2012; Abrams 2014; St. Pierre 2015), pregnancy and childbirth (LaChance Adams and Burcher 2014), and aging and death (Cuffari 2011; Heinämaa 2014; Weiss 2017). Phenomenologists have articulated the ways in which these particular aspects of human experience transform foundational conceptions of

selfhood, relationality, belonging, and affectivity. These discussions mark a promising shift in the uptake of phenomenology: the study of novel problems outside the scope of traditional phenomenology is important for our understanding of bodily changes and particularities that are constitutive of human experience. As evidenced by this research, the value and meaning of cultural and philosophical categories of illness and health are still largely unresolved. Overall, this research illuminates the extensive possible applications and continued relevance of phenomenological inquiry.

In what follows, I offer a phenomenological account of my lived experience with mental illness. My general interest is in the experience of serious disorientations in illness, with a particular focus on mental illness. Through this account, I reexamine phenomenological concepts of home (or being-at-home) and belonging and explore how illness casts a new light on these notions as they relate to embodied ways of becoming oneself. Tracing the relationship among illness, home, and belonging, I bring into focus Ami Harbin's and Sara Ahmed's notion of disorientation (Ahmed 2006; Harbin 2014, 2016) to describe my personal experience of being diagnosed with borderline personality disorder (BPD) and living with mental illness. In various ways, illness has disruptive consequences for an individual's life. Its uncharted consequences upheave acquired bodily dwellings and threaten familiar horizons and ways of being in worlds. The disorientations brought forth by illness call into question unexamined assumptions about what it means to become oneself, to belong someplace, and to begin to feel *at home* in the world. I argue that they can also bring forth beneficial forms of self-awareness and I suggest tentative pathways to alternative forms of habitability. This article thus also examines how the (in)stability of bodily dwellings in experiences of disorientation can suggest ways of being in the world that are more attentive to interdependency, unpredictability, and change in human experience. By asking what it means to recognize our bodies as volatile and fragile homes and by complicating unequivocal claims to being-at-ease, my hope is that this reflection can strike a middle ground between the anxiety to belong and the experience of estrangement in illness.

Section I of this article outlines my central methodological commitments. In writing through my own experience of living with mental illness, I find support in a framework centered on feminist and phenomenological approaches to embodied experience. These complementary strategies recover valuable sites of engagement for our understanding of experiences of mental illness, such as the personal and relational importance of embodiment, its entanglement in cultural representations of illness and health, and its significance for our experience of belonging. In section II, I offer a narrative of my lived experience of being diagnosed with BPD and living with mental illness. This section builds on Ami Harbin's and Sara Ahmed's accounts of disorientation to describe the difficulties of feeling at home in illness, in light of the assumed *homelikeness* of health. In view of these concerns, section III foregrounds the importance of building a sense of home in finding one's place in the world and offers a phenomenological analysis of the intersection of embodiment, home, and belonging. Through a discussion of the phenomenological importance of body-world relations, I anticipate the consequence of illness on the ideal of belonging as seamless

compatibility. In section IV, I suggest that dwellings in illness might function as a more capacious and apposite metaphor to account for the variability and unpredictability of our ways of being and feeling at home in the world. This section highlights the central role of others in creating a time and place for the experience and expression of disorientations, in and through material-discursive processes of shared world-making. This discussion further outlines the ethical and political importance of building worlds that make room for different ways of being at home through our interactions with others. Although my discussion does not *supply* norms for ethical action, I contend that a feminist phenomenology of illness generates saliences and illuminates sensibilities that can transform our ways of being with others.

I. A FEMINIST PHENOMENOLOGY OF ILLNESS

From a phenomenological perspective, an important problem with traditional biomedical approaches to mental illness is the strict differentiation between objective and subjective levels of analysis in clinical research and observation. Put coarsely, clinical third-person perspectives on illness are limited to observations on a patient's "objective" physiology. Although this viewpoint captures the biomedical fact of disease and psychopathology, it leaves out first-person experiential accounts of mental illness and is generally unfit to account for everyday experiences of our own bodies. Both subjective and objective perspectives intersect in our own and others' perception and representation of healthy and ill bodies. To this effect, the significant gap observed between patients' reports of various types of bodily symptoms and illnesses, on the one hand, and etiopathogenetic theories and clinical diagnoses, on the other, is particularly concerning (Sestito et al. 2017), given the influence of neurological reductionism and concurrent promissory rhetorics of recovery in approaches to mental illness, to the detriment of patient experiences and priorities (Reardon 2014). This disparity between patient reports and medical theories also maps onto larger ethical and epistemic concerns about the place given to the voices and experiences of those immediately affected by illness in medical discourse and the perceived legitimacy of their claims to suffering (Crichton, Carel, and Kidd 2017; Kidd and Carel 2017, 2018). More generally, this gap undermines the richness of our understanding of mental illness and the quality of our ways of attending to it (for example, through institutionalized care).

Promising alternatives to strictly biomedical discussions of illness now increasingly include approaches that harness phenomenology's focus on lived experience (Zeiler and Käll 2014; Carel 2016a; Aho 2018). In its original formulation, phenomenology offered a study of the universal (or eidetic) structures of consciousness. However, its interest in embodiment also makes phenomenology a study of situated and singular experience. This productive tension between the study of shared features of experience and the facticity and particularity of bodily difference is at the heart of contemporary feminist and critical phenomenology. Overall, these approaches generate a relevant methodological toolkit for our in-depth understanding of this tension.

Critical and feminist phenomenologies have also made central the interplay between intersubjective (or shared) horizons and first-person experience (Ahmed 2006; Guenther 2013; Oksala 2016; Salamon 2018). By revealing the anchorage of meaning in shared human experience, approaches centered on the experience of disorientations in serious illness can help recover its richness and complexity. The central conviction that informs this article is that fine-grained phenomenological descriptions and narratives of the experience of illness provide useful insight into its meaning and structure in ways that elude traditional medical explanations.

In its current state, a biomedical understanding of mental illness lacks an exploration of the dynamic coexistence between the body as a neurobiological entity and the body as those suffering from psychopathology experience it. This important distinction between the body as a neurobiological entity (or body-object) and the experiencing body (or body-subject) helps differentiate the physical body as a substrate of disease, and the lived experience of ill-embodiment. The distinction has, however, been extensively discussed by phenomenologists such as Edmund Husserl and Maurice Merleau-Ponty, and following them, Simone de Beauvoir and S. Kay Toombs, to name only a few (Beauvoir 1949; Husserl 1989; Toombs 1993, 2010; Merleau-Ponty 2012). In fact, a central outcrop of phenomenology's philosophical attention to the body is the distinction between the body as object (*Körper*) and the lived body or the body-as-subject (*Leib*). Phenomenologists typically argue that although we *can* actively reflect upon our experience and thematically examine or conceive of our own body as an object in the world (for example, when experiencing severe pain or studying human anatomy in a laboratory), we go through most of our lives not doing so. Instead, in everyday experience, our bodies are simply mediums for our being in the world. They are our means of embracing a friend, riding our bikes, looking for a missing sock, or doing things that matter to us in ways that have become largely habitual.

This primary, prereflexive layer of experience corresponds to our most intimate sense of ourselves as the bearers of our experiences. Phenomenologists thus distinguish between our body as a living organism and our body as the *locus* of our embodied consciousness and agency. This important experiential distinction illuminates the ambiguous interplay of objective and subjective dimensions of embodiment. By returning to lived experience, phenomenologists also recognize the essential situatedness of lived experience: the interplay of biological, affective, cultural, expressive, and sociohistorical horizons of lived experience shapes the skein of meanings and bodily commitments that determine our situation in the world. In encompassing these broad horizons, phenomenology further departs from rigorously objective biomedical approaches to human life. Instead, it draws into focus the embodied, situated, and relational ways in which subjects engage with a shared world. These methodological touchstones ground my analysis of disorientation in illness.

Reciprocally, I argue that the experience of illness can potentially generate a philosophical awareness that enriches traditional phenomenology and refine our understanding of key concepts, such as home and belonging. Without falling prey to a view of illness and serious disorientation as desirable and *inherently* morally edifying

or virtuous experiences, I argue that they are nonetheless philosophically important. The potential outcomes of illness that I outline in this article, however largely dependent on one's sensibility and social situation, warrant for illness a critical role in the articulation of alternative livable and legible forms of embodiment and habitability. Although doing away with the medical prevention of pain and suffering does not seem desirable, my claim is that a closer consideration of the existential (or lived) dimension of illness is required to fully understand these experiences and develop more sensitive and humane approaches to care. Put briefly, a phenomenology of illness examines the way in which illness is lived and experienced by individuals, but it also reveals the embeddedness of these experiences in dynamically unfolding modes of relationality and sociality. On such a view, the application of a phenomenological framework to the study of illness is important beyond the individual level of analysis and behooves us to produce descriptions that can have validity and interest across populations, experiences, and theoretical approaches to human life. This phenomenological approach to illness stresses the meaning and experiential features of *ill embodiment*. It insists that experience is the product of our engagement with the world as fully embodied beings situated in and *in-between* places, cultures, norms, and practices.¹ From a phenomenological perspective, the relational and dynamic encounter between body and world is key to our understanding of the nature of bodily subjectivity and the experience of illness, and it becomes clear that we can only ever secondarily access an abstract or detached theoretical standpoint from this experience.

Although this reflection draws insight from traditional phenomenology, it aligns most productively with feminist phenomenological scholarship and its discussions of women's experience of their bodies (Beauvoir 1949; Bartky 1990; Young 2009; Weiss 2013). Feminist phenomenology plays an invaluable role in illuminating the gendered dimension of lived embodiment. More broadly, feminist phenomenological scholarship highlights the ways in which identity categories affect our ways of being in the world and having this recognized by others. In keeping with phenomenology's rejection of naturalistic reductionism, feminist phenomenology makes visible the irreducibly situated and contextual nature of (gendered) bodily subjectivity. It extends and vitalizes traditional phenomenology's unique concern for the centrality of human embodiment. Feminist phenomenological approaches to embodied experience thus work against the grain of a "universalizing view" and offer up instead our concrete situation in the world as a privileged starting point to probe the meaning of our experiences.

This approach to embodiment contributes an analysis of the entanglement of bodies in structures of power and its normative implications for the stigmatization of (bodily) difference. To this end, feminist phenomenologists also offer key contributions to a discussion of the normative assumptions underlying the pathologization of "bodily difference, vulnerability and volatility" (Zeiler and Käll 2014, 1). This concern brings feminist and phenomenological approaches into deep accord. Both emphasize the importance of lived bodily experience for our understanding of how and why we incorporate and reproduce habitual and taken-for-granted ways of inhabiting the world. Unscrutinized assumptions about the value and meaning of

human life, including life in illness, translate normalized conceptions of health and ability. They reproduce expectations of “natural” bodily comportment, cognition, style, and mobility at the expense of those who fall outside these lines. Thus the normative constraints that arise from our perception and categorization of bodies contributes to consolidating binary categories such as healthy or sick (Toombs 1993, Carel 2016a, 2016b; Freeman 2018), able or disabled (Erevelles 2011; Herndon 2011; Kattari, Olzman, and Hanna 2018), sane or mad (Kafai 2012; Wolframe 2013), and normal or abnormal (Wehrle 2015, 2016, 2017; Weiss 2017; Jansen and Wehrle 2018). These notions, along with many others (for example, race, gender, class, sexual expression), converge in our own and others’ representation and perception of our bodies (Ahmed 2006; Alcoff 2006; Al-Saji 2010; Hall 2011), coiling personal and shared social horizons. For such reasons, the intersection of systems of privilege and oppression holds immediate importance for embodied experience, including life in illness, and illuminates the inherently intersubjective textures of lived experience. Perceptions of normative and nonnormative forms of embodiment also percolate in medical theory and practice and give rise to various forms of discrimination and institutional control. This is particularly relevant to understanding how clinical encounters and healthcare systems can function as spaces of increased bodily vulnerability, exposure, and scrutiny, and generate added layers of oppression for members of oppressed and/or nondominant social groups (Barned, Lajoie, and Racine forthcoming).

Theorists have also made evident how relations of power cause an uneven distribution of authority and recognition to various groups, not the least of whom are individuals living with mental illness. To this effect, the case of BPD diagnoses is particularly striking. Studies show that women receive BPD diagnoses three times more often than men do (Nehls 1998; Skodol and Bender 2003), leading researchers to speculate about diagnostic biases.² Feminist scholars have leveled important criticisms and expressed concerns about the medicalization of trauma and suffering experienced by women diagnosed with BPD (Shaw and Proctor 2005; Berger 2014). Others have pointed out a notable phenomenological overlap between the classificatory scheme of BPD and the diagnoses of women with symptoms of hysteria in modern psychiatry (North 2015). The heavy stigma surrounding BPD and its folk-characterization as the “crazy bitch syndrome” have also led feminist practitioners and patients to wonder how gender inequalities and clinical biases lead to punitive applications (Lewis and Appleby 1988), as well as frame this diagnosis in folk psychology and popular opinion.

Although a comprehensive reading of gender biases in clinical responses to mental illness is beyond the scope of this article, it is worth noting that in writing as a woman living with mental illness and a diagnosis of BPD, I am equally concerned with the intersection of representations that assign my body as *woman* and as *ill*. These types of assignments trace expectations through which subjects orient themselves and come to feel at home in the world. To varying extents, they shape my relation to the world and my bodily inhabiting of its spaces, as well as anchor my discussion of disorientation in illness. In writing of living with mental illness and a

diagnosis of BPD, I describe illness as a fundamentally embodied experience involving one's orientation (and situation) in the world, along with relations to others. As such, I do not take mental illness to be a strictly cognitive experience or a discretely psychological phenomenon. As Jo Ann Walton formulates it in her account of the lived experience of mental illness, "[people] experience illness in their whole being" (Walton 2001, 279). Following Walton, I further claim that we know and experience belonging in and through *our whole being*. I take this holistic approach to illness and belonging to be compatible with the phenomenological conception of the lived body. From a phenomenological perspective, the lived (or experiencing) body is the medium of our existence in the world. As a medium, it is expressive of our relation(s) with the surrounding environment and is wholly engaged in each of our experiences, albeit often tacitly. Illness engages the lived body itself, through its relation with the previously outlined overlapping horizons of experience. I contend that disorientations in illness threaten to splinter the coherence of these horizons and erode familiar orientations. As I hope to show, these failures or fault lines in orientation have important consequences for belonging, at least in its formulation as seamless body-world compatibility. On this view, I am not interested in the neurological substrate of mental illness, but rather in the qualitative saliences and shifts that modify one's embodied orientation in the world in illness. In writing about ill embodiment, I do not wish to cast illness as a monolithic fact of the body or congeal it as a natural given. Instead, my aim is to describe ill embodiment as a deeply transformative and fundamentally intersubjective experience. Although mental illness is not visibly identifiable in ways that other illnesses and disabilities might be,³ it impels concrete, visceral bodily changes in my experience of the world. This liminal experience traces ways in which I orient and reorient myself in and through the sensibilities that it reveals and their importance for belonging.

II. DISORIENTATION IN ILLNESS

I received a BPD diagnosis at the age of sixteen from a team of health professionals in the mood-disorder branch of a large psychiatric hospital, after a string of psychiatric evaluations. In the following weeks, my psychiatrist and therapist recorded and monitored a number of co-occurring issues (an eating disorder, major depression, and obsessive-compulsive traits). According to the American National Institute of Mental Health, "[borderline] personality disorder is a mental illness marked by an ongoing pattern of varying moods, self-image, and behavior" (NIMH 2017). In the DSM-V (Diagnostic and Statistical Manual of Mental Disorders, 5th edition), BPD is classified in the broader category of personality disorders, alongside nine other diagnoses. The DSM-V lists signs of marked impairments in personality functioning (including poor and unstable self-image) as well as instability in self-direction and sense of purpose as key diagnosis criteria. Pathological personality traits associated with BPD also include emotional lability, chronic feelings of apprehension and uncertainty, disturbances in personal and interpersonal functioning, depressivity, anger, anxiety and

suicidal ideation, as well as self-damaging impulsive behaviors (American Psychiatric Association 2013).

A diagnosis of BPD is commonly associated with an excessive sensitivity to environmental circumstances and interpersonal dynamics. Interpersonal functioning in patients with BPD is described as being compromised and impaired by “frantic efforts to avoid real or imagined abandonment” (APA 2013). Perceptions of impending loss, rejection, and separation “can lead to profound changes in self-image, affect, cognition and behavior” (APA 2013), particularly when individuals fear that they are not being supported and understood by others. Clinical reports on patients with BPD include observations of unpredictable and uncontrolled mood swings along with intense, shifting, and totalizing ways of experiencing life events and interpersonal relationships, all leading to marked instability. Overall, the impairments in personality functioning reported by these descriptions coalesce into a bleak picture of emotional suffering and pathological instability.

Notwithstanding compelling concerns over the general relevance and accuracy of psychiatric classificatory strategies,⁴ and despite these given characterizations, BPD has often been designated as “one of the most problematic diagnostic categories to emerge from the DSM” (McDonald, Pietsch, and Wilson 2010, 86). BPD itself is a “border-diagnosis.” Clinicians do not entirely agree on the best way to define it in large part because it “[lies] near the boundaries or borders of other mental illness categories” (86). The variety of its professional interpretations complicates the location of BPD on the map of diagnostic categories. The definition of BPD, then, is itself debated territory. In addition to these challenges, research on BPD is still largely underfunded and incommensurate with the level of psychosocial issues and psychological suffering with which it is associated (Zimmerman and Gazarian 2014). BPD also remains one of the most stigmatized diagnoses to emerge from the DSM: extensive research shows how individuals diagnosed or identifying as living with this illness confront stigma (including self-stigma) and stereotypes both in society and within healthcare settings (Nehls 1998; Aviram, Brodsky, and Stanley 2006; Grambal et al. 2016; Sheehan, Niewegłowski, and Corrigan 2016). Arguably, this makes it difficult for patients living with BPD to benefit from a clear picture of their diagnosis and register its consequences. In my experience, given the authority of cultural and medical discourses on pathology in the regulation and reification of experiences of illness, this level of clinical uncertainty led to frustration, anguish, and deep-set confusions about who I was and where I belonged.

My first memories of illness include countless nights spent lying awake in bed, washed over by inexplicable tides of sadness and explosive anger. I imagined huge bodies of water that arched and broke, engulfing *my whole being*. My experience of this body and this being *which I was*, but for which I could not find a proper time and place, contained everything I knew or did not know about myself. I spent the weeks before I entered the psychiatric hospital in a haze, feeling hopeless and drained. I had been experiencing symptoms of depression for over four years, and it seemed as though things had reached a tipping point. The smallest things could break me: the effort required to engage with others, my reflection in the mirror, or a

body brushing against mine. Diagnosis aside, I knew that my biggest struggles had always been low self-esteem and enduring feelings of emptiness and depression. As a young woman, I struggled to find a home in my body and suffered from severe body image issues. I wrestled with persistent self-hatred and experienced dissociative episodes in which I imagined myself being finally rid of my own body. I grew up seeking intimacy and closeness most desperately when overcome with a fear of being unmoored from and abandoned by the care of others, despite growing up in a loving home. Overall, my struggle to attune myself to the world and to beneficial forms of affective intimacy uncovered deep ontological insecurities about my general orientation in the world and the ways in which it was read by others.

At times, it is as if this lump of flesh *which I am* is wrapped in the thinnest cloth, and nothing else. Because this cloth is so thin, it is easily unlaced or undone by life events, irrational fears, or the onset of an inexplicable sadness. In particularly difficult times, I feel as though every thread running between me and the world is loosened until I slip entirely between my own fingers. This feeling, although it is extremely difficult to capture in words, is absolutely terrifying. I can remember, from a very young age, experiencing what I can now describe as an uncontrollable fear of being pulled away from the comfort and security of spaces and relationships that suddenly refused to extend and make room for the shape of my body. If I had to describe this experience now, I would say that it is a feeling of being riveted to myself and yet constantly uneasy, disoriented, and out of place in a world that feels like a strange lump of flesh, rather than like anything wondrous, powerful, or alive. It is a feeling of experiencing my body primarily as a thing in a world of things and only rarely as a living being with a grip on the world and sharing it with others, all linchpins of a certain bodily phenomenology of belonging (Ratcliffe 2009).

My experience of illness queered the ways in which I think about belonging in the world and in my body. As a woman living with mental health issues, I struggled to feel at home in either and experienced both this diagnosis of BPD and my mental illness as significant disorientations. Although the focus of this article is my lived experience of mental illness and not the medical diagnosis itself that I was assigned, the categorization of health states (or lack thereof) is an important underlying concern for phenomenological discussions of mental health. To this end, my relation with BPD is extremely ambiguous. Oftentimes, I have found myself negotiating, both in my relationship with myself and in those with loved ones, the capacities and limitations afforded to me by a diagnosis that is at once relieving and burdensome. This new diagnosis made me feel like an invisible force could twice over infringe on my comfort and intimacy or pull the rug out from under my feet, and the effects of receiving a diagnosis and being medicalized at a young age were disorienting.⁵ Its consequences registered at a personal, embodied, and discursive level, through the exigent task of learning to live with a new understanding of myself in the selfsame body. I am more interested, however, in the subtler and deeper-running disorientation that I experience as a woman living with mental illness, and its consequences for belonging.

Per Ami Harbin, disorientations are “temporally extended, major life experiences that make it difficult for individuals to know how to go on” (Harbin 2016, 2). These multidimensional experiences speak minimally to the state of feeling “not at home in body, affect, and thought” (100). Elsewhere, Harbin describes experiences of bodily disorientation as being indicated by “feelings of being out of place, unfamiliar, or not at home” (Harbin 2012, 262). In her account of (dis)orientation, Sara Ahmed highlights a similar connection with place when she writes: “Disorientations can be a bodily feeling of losing one’s place, and an effect of a loss of a place” (Ahmed 2006, 160). Disorientations in our sense of home, then, involve bodies finding worlds “that do not extend their shape” (160). Although they have been given little philosophical attention thus far, disorientations constitute an important part of human experience. They are not an oddity: rather, all of us will encounter these types of experiences at least once in our life, albeit with different levels of exposure (for example, through trauma, aging, grief, illness, racism, queerness, or migration). In virtue of unjust social structures and dominant norms, some individuals, groups, and communities will be disproportionately exposed to or protected from specific types of disorientations. Additionally, although most disorientations can be upsetting and disturb central aspects of our lives, not all disorientations are harmful in the same way: considerations of race, gender, class, ability, and sexuality all play a part in the ways in which we experience and respond to serious disorientations.

By suggesting that orientations in the world throw the world up and disrupt what we often took for granted, both Harbin’s and Ahmed’s accounts capture the difficulty of navigating experiences of disorientation. Orientations are foundational in the production and driving force of normalcy:⁶ they trace habitual and normative ways of being in the world and play an important role in our inhabitation of spaces as homes. Conversely, the possibility of losing one’s grip on home anchors the constitutive role of un-homelikeness, estrangement, contingency, and unpredictability in human experience. My suggestion is that these elements are important for our understanding of disorientation in illness. In this next section, I discuss the connection between phenomenological notions of embodiment, home, and belonging. My hope is that a multipoint engagement with these notions can indicate paths to more liminal, precarious, or fragile ways of being at home.

III. BEING AT HOME

I arrive at the concept of home from the notion of (dis)orientation by imagining being at home as a particular way of *being oriented* in the world, marked by coherence and familiarity. In what follows, my interest is in belonging as phenomenologically synonymous with *being at home*. I argue, however, that this account of belonging can and must also accommodate and make room for experiences of disorientation. To this end, I analyze and work to expand the notion of belonging as body–world compatibility (or optimality) to include consideration of phenomenological variations in ways of feeling at home. Because body and world are so intimately bound, the

ideal of a seamless fit between them has the appeal of stability and offers this fit as a nexus for belonging. However, this ideal excludes the experiences of individuals living in liminal, precarious, or labile states, and hollows out claims to alternative forms of bodily dwelling. Put briefly, I argue that a blanket notion of home does *not* function as an apposite metaphor for a life in which serious disorientations are possible. Without surrendering the importance of home, this section opens the way to a discussion of richer and more capacious notions of habitability and belonging.

As many have argued, home is a personal and political question that needs demystifying and that has often functioned to conceal the exclusivity of memberships and solidarities built in its name (Reagon 1983; Young 2009; Ortega 2016; Dolezal 2017). In their discussion of the configuration of home and community for feminist politics, Biddy Martin and Chandra Talpade Mohanty highlight the rhetorical appeal of “home” as ground for unity and stability (notably in white feminist politics) and the importance of its careful re-examination as a metaphor (Martin and Mohanty 1986). “Home” conjures social, cultural, domestic, geopolitical, racialized, and gendered horizons that all work as background for one another in the institution of livable and legible forms of belonging. As Mariana Ortega writes, thinking of homes “can thus lead us from the confines of our own skin to the open spaces of worlds inhabited by others like and unlike me” (Ortega 2016, 194). Being at home is both a foundational bodily experience, hence Ortega’s reference to the confines of our skin, *and* a function of dynamically unfolding modes of relationality and sociality. As such, although many types of belonging are not about one’s physical “home” per se, I argue that they are minimally cued by embodied feelings of being at home (or *homelikeness*). As volatile or problematic experiences of home teach us,⁷ the privilege of a safe and fixed abode does not describe all experiences of home and belonging, nor does it encompass all types of shelters. Instead, as I will show, a univocal conception of home redacts the experiences of individuals inhabiting less-stable dwellings. Drawing on this intuition, I connect the notions of illness, home, and belonging through a phenomenological analysis of variations in ways of being oriented and coming to feel at home in the world.

The experience of belonging is typically described as a feeling of closeness, kinship, or intimacy with a particular setting, place, identity, or community that extends one’s presence and makes one feel *at home*. When thinking back to our first experiences of feeling at home, some of us will remember the first place in which we lived. Memories might bring to mind the texture of the drapes or linens, the steps taken on staircases and in hallways, the voices from neighboring apartments, the quiet or bustling streets, the lighting of a particular room, or the smell of a home-cooked meal. More than a place, however, most will agree that feeling at home also designates something closer to a general state of being, independent of one’s objective physical location and surroundings. This is roughly what we mean by such colloquial expressions as “home is where the heart is,” “home is a person,” or “home is feeling.” Hence we might feel quickly “right at home” in a new environment or community if and when we have been made to feel welcome by those who share it. To the contrary, a nagging sense of being “out of place” might emerge in the most familiar setting, due

to a change in perception, a new interpersonal dynamic, or simply the wear of time. It seems that our deepest sense of being at home has something to do with the fine-grained experience of being oriented. When we are oriented, we are held and supported by spaces that feel “like a second skin that unfolds in the folds of the body” (Ahmed 2006, 9).⁸ Hominess captures the feeling of being in the right place at the right time. In light of these considerations, it could be said that belonging captures a form of bodily dwelling marked by our situation and orientation in the world: it describes the quality of one’s attunement to the world as *home*, and the embodied experience of body–world compatibility and complicity that it enfold.

In her analysis of home, Kirsten Jacobson draws an important connection between embodiment and belonging and argues that home is phenomenologically akin to the body. Jacobson offers everyday descriptions of the experience of feeling at home to describe home “as a place of and for the self, [a] situation of refuge for us” (Jacobson 2009, 357). In Jacobson’s description, homes are shelters where we can let go, if only for some time, of the constant solicitations and requirements of the “outside” world. Home is a place where we find both quietness and grounding, “a place of *self-nourishment* and *self-development*” (359). As such, writes Jacobson, “[at] the most basic level, home is like the body insofar as it is. . . a place of initial stability and a foundation for the self” (361). This stability and sense of foundation form a passive layer of experience rooted in the space of the body, and afford our experience its breadth, coherence, and familiarity, along with our lives their primary dwelling. In claiming that our first home and the ground of our experience of belonging is the lived body itself, Jacobson’s argument about the home-body finds support in the writings of phenomenologists like Husserl and Merleau-Ponty. Jacobson’s argument is phenomenologically sound, and it helps illuminate the fundamental role played by our bodies in orienting us through the world and rendering it *habitable*. For Husserl, our body determines our (the subject’s) “near sphere” or “primordial core sphere,” which Husserl also calls our “core-world” (Husserl 1989, 149–50), or “zero-point of orientation” of the subject. Merleau-Ponty similarly stresses that the body serves as the “here” from which we stand; it is from this place—he lived body itself—that we encounter the world and find our way.

On such a view, it seems that our most foundational sense of belonging and being at home has more to do with a deep-running sense of orientation buoyed by the body than it does with any sort of active conceptual operation. Arguably, then, a subject feels most at home in the world when she moves effortlessly through her environment by relying on embodied, prereflexive habits, and encounters others and objects as familiar sights. The phenomenological notion of motor intentionality highlights how modes of bodily recognition enable us to encounter the world as an open situation and anticipate through our bodies appropriate motor reactions. Through habitual and familiar layers of experience, and with the assistance of our proprioceptive sense, our bodies move inconspicuously through space, orient themselves, and skillfully navigate the rooms, landscapes, terrains, and situations that they meet. Phenomenological literature abounds with such references to the balanced coupling of the lived body and its environment. To this end, authors regularly refer to an

“average” body that forms with its surroundings a prereflexive, practical system and most often seamlessly integrates with its environment, orients itself in space, and “[saturates] the space with body matter” (Ahmed 2006, 9).

Per Merleau-Ponty, our body is *optimally* geared into its environment when it provides us with a richly differentiated and coherent stream of experience (Merleau-Ponty 2012). Our body enables us to establish significant landmarks and pathways in view of the accomplishment of meaningful tasks and projects. Simply put, from a phenomenological perspective, being at home grants one the privilege of an indistinguishable fit with the world. The space of this connection and the different ways in which it is negotiated form the basis of our claim to belonging. Traditional phenomenological accounts of a harmonious extension of the lived body in space and its seamless compatibility with its surroundings capture an important aspect of human experience. Nonetheless, they miss countless other ways in which bodies inhabit the world. Descriptions of “inconspicuous, unobtrusive, and nonobstinate” (Diedrich 2001, 212) forms of belonging fall short. They do not account for embodied feelings of disorientation, unease, queerness, misfit, alienation, or jarring incompatibility.

Various moments in life introduce fleeting or more ground-shifting changes that alter our perspective and render conspicuous the precarious status of bearings or beliefs that we had secured. One can simply think of turning around quickly when hearing one’s name being called out and seeing the room veer off for a second. Disorientations that are more serious might include the onset of illness or old age, grieving the loss of a significant relationship, experiences of migration or of living between worlds, or the harms of oppression. When the body is oriented, it is ready to act and able to confidently extend into space in a kind of osmosis. Inversely, being disoriented is a lot like becoming an object in space and feeling one’s motor and expressive abilities curtailed. By virtue of its openness to various transformations and vulnerabilities, embodied existence is largely unpredictable. Inasmuch as we are constantly involved in material and discursive interactions with our environment, harmonies and disjunctions may occur. Occasional breakdowns can disrupt or soften our strongest sense of mastery and warrant self-examination, by “[exposing] the relational component and the fragility of fitting” (Garland-Thomson 2011b, 597). More so, these experiences of disorientation are rooted in the often-shifting grounds of our existence and bring to our attention the fragility and contingency of acquired dwellings. In this light, experiences of disorientation also mark an upheaval of the general order of sense and predictability in which things stand.

For individuals falling outside the lines of compulsory able-bodiedness and able-mindedness, it has long been evident that conventional notions of home and belonging are rooted in cultural beliefs about the value and moral praiseworthiness of “stable [and] enduring identities” (Garland-Thomson 2011a, 33). These beliefs fail to give serious philosophical attention to the wide spectrum of bodily experiences and to reckon productively with ambiguity, instability, and change.⁹ In my experience, acknowledging that some level of disorientation cannot be entirely expended has functioned as an important survival strategy in illness. The disorientations in illness that I have described will arguably be a part of anyone’s life and hold valuable

insight. In what remains of this article, I explore how dwellings in illness serve to undermine the fantasy of the liberal individual as a stable, sovereign, and entirely self-governed entity. Instead, I suggest pathways to a relation with the world and others that are more closely attentive to “the inherent instability of the embodied self” (Garland-Thomson 2011a, 17) and the uncertainties it can prompt.

IV. THE ROLE OF OTHERS: A TIME AND PLACE FOR DISORIENTATION

In this last section, I suggest that our understanding of belonging can and should be expanded to account more inclusively for variations in human experience. I examine the ethical and relational importance of creating a time and place for the experience and expression of disorientations. My claim is that although disorientations can have disabling consequences, some types of breakages, losses, and disorientations can *also* function as pathways to different modes of belonging, in and through the recognition of the fragilities of embodied existence and the creation of different homes for our bodies. This section opens the way to a discussion about the importance of developing alternative pathways to habitability through our interactions with others. Conversely, I suggest that discriminatory attitudes and stigmatization compound the harmful consequences of disorientations, and redact the contributions and experiences of individuals living with mental illness.

In section II of this article, I described my experience of feeling undone and unlaced from my anchorage in the world. In the early stages of my struggles with mental illness, there were times when I felt it was impossible for someone like me to ever belong anywhere, if belonging meant feeling my body perfectly entwined with and enfolded by the world. In this sense, I experienced my body as being *ill-fitted* for the world. Whereas it seemed as though everyone around me carried himself or herself with unreflective ease, I struggled to complete even the most trivial tasks (for example, getting dressed, holding up my end of a conversation, walking to the bus stop). The somatic and affective dimensions of emotional suffering troubled otherwise unexamined elements of my everyday life. My body seemed to be closing down and refused to respond to its surroundings dynamically, as is usually the case in responsive intentional experience.

In my view, Harbin’s notion of disorientation is key to a renegotiation of the notion of belonging around human variation that also makes central the possibility of existential transformation and moral growth. Her most venturesome claim, then, is that although disorientations typically strike us as negative experiences, the various ways in which subjects are challenged by these disorientations can play a significant role in their development and prompt important changes in personal and relational practices. Although they disrupt habitual ways of relating to oneself, to others, and to the world, disorientations can also bring about a qualitative shift in our experience. Over time, I have come to understand that interruptions, failures, or changes of pace in the flow of experience require my care and attention. These variations in rhythms and capacities are part of the understanding of belonging I have created for

myself. Although complicated by the experience of living with mental illness, my sense of belonging finds subtle and nuanced ways of expressing itself. It is dynamic and adaptable, as well as cognizant of its limits. Through my experience of illness, I have gained a richer awareness of the complexity of our encounters with the world. Overall, this awareness is a tool to navigate disorientations through the cultivation of “more tentative, sensitive, and less sure-footed ways of being” (Harbin 2016, 63).

Although I could not rid myself of the deeply unsettling effects of a felt loss of vitality, autonomy, and resoluteness, my experience held a subtle and yet transformative potential. As Harbin writes, illness “introduces the need to pay attention to our own or others’ bodies more than usual, to care for them differently, or to stop using them in ways we have done unthinkingly in the past” (Harbin 2016, 100). This shift, however, is not always entirely debilitating.¹⁰ Disorientations can also function as a site of reflexive awareness that is revealing of previously unexamined relations, expectations, and discourses, thus providing key ethical import. Disorientations can reveal understandings of health and ability that ripple outward and transform our orientation in the world. When harnessed and supported by others, disorientations have implications for our ability to recognize our own and others’ vulnerabilities. New sensibilities acquired through the experience of illness might teach us to accept unpredictability and better appreciate situations of reciprocal dependency. Illness can thus bolster a more layered understanding of differences in shared practices of home-making and foreground the importance of learning to live “in a world of unpredictability, vulnerability and interdependence” (Harbin 2016, 121). These disorientations, then, are not to be conceived strictly as loss. In changing how we inhabit the world, disorientations in illness are also conducive to a richer and more capacious understanding of human experience. Precisely because they queer how we think about the value and meaning of human experience, first-person accounts of mental illness can and should open up spaces to reflect on and “[recognize] our disorientability” (169).

These claims point to the importance of recognizing disorientations as an important and shared feature of human experience. Disorientations in illness can teach us that our relationship with the world is *not* best described by a robust or unequivocal sense of home and belonging. Instead, as new elements in our life gain salience, familiar notions ask to be revisited. Rearranging our bodies and conceptions of belonging along different axes or through new orientations can mean different things for different individuals. For some, it might mean refusing the imperative of recovery (or curative time) as the only possible answer to mental illness. Others might choose to embrace an ambiguous positionality in illness, or what Shayda Kafai describes as “alternative locations of being” (Kafai 2012). In advocating for a disruption of the binary between madness and sanity, Kafai’s description of her experience with manic depression examines the possibility of grounding herself in a third (or alternative) positionality and of thus “[arriving] at a resting place within [herself]” (Kafai 2012). For others, it could mean embracing the diagnoses they are assigned and building communities around a shared experience in illness. This can be done both in and out of medical or psychiatric settings, with or without the immediate involvement of healthcare professionals. However, I would argue that in all of these cases, lack of

support and stigmatization severely injure and harm this process for marginalized individuals.

To this end, I largely agree with Harbin's claim that the promise of "habitability" for disoriented individuals is fundamentally relational (or intersubjective). As Harbin aptly points out, disorientations occur "in the midst of relations with others" (Harbin 2016, 154). She stresses that we have a responsibility to acknowledge ourselves as individuals who can be disoriented, as well as open ourselves to those disorientations experienced by others. Harbin thus draws an important distinction between attempts to reorient "disoriented" individuals, and efforts to create spaces supportive of the experience and expression of such disorientations. She writes: "The main function of others as toeholds is not to interact with us in ways that reorient us, so much as to meet us in ways that make disorientations livable" (168). Admittedly, by attending more carefully to the experiences of individuals living with mental illness in ways that do not immediately reorient them, we open ourselves up to a more attentive and careful parsing of these stories. This type of trained sensibility or properly phenomenological attention to lived experience expands our ways of caring for and being with others.

Precisely because experiences of disorientation conflate with feelings of fear, uneasiness, and discomfort at having one's abilities curtailed, they require places in which to exist and be explored in ways that do not immediately override their expression. The question of what it might mean to create these spaces is a difficult one. It cannot mean simply offering individuals living with mental illness *a seat at the table*, if we are still assembling around the same tables or gathering in the same places and in the same way. We should fight for access, but we also need to ask what we are fighting to access when we are fighting to sit at the table. Mia Mingus writes, of disability justice: "We don't want to simply join the ranks of the privileged; we want to dismantle those ranks and the systems that maintain them" (Mingus 2011). The shape of these tables, then, must tell another story of belonging altogether.

Pathways to alternative forms of habitability do not point to a distinct accomplishment in time, nor do they describe a linear process. Perhaps one of the most promising claims made by Jacobson in her discussion of home comes shortly after her preliminary description of the home-body. Homes, she writes, are not always discrete, self-evident entities. They are not given to us at birth, but rather "we are responsible for making our home... and this is something we must learn how to do, and that we learn to do with and through other persons" (Jacobson 2006, 362). Ultimately, this responsibility for making our home comes with a responsibility to build these homes through dialogues and exchanges in ways that aim to make the world habitable for others. One of such homes for me was the community of people who recognized illness as a significant part of my life and adopted a critical attitude toward unexamined expectations and standards of health and sanity. Along with me, they discovered the harrowing heights and melancholic lows of illness. With equal parts resilience, compassion, and humility, this community carves a world in which I want to live, where I can hope to feel at home, and that we find ways to share. The role of

others in creating a time and place for disorientation is, in itself, a catalyst for new orientations.

V. AN ETHICS OF EMBODIMENT

In this article, I have developed an account of my experience of mental illness as disorientation, in view of a reevaluation of conventional phenomenological notions of home and belonging. I employed a feminist phenomenological framework to describe my experience of my own body as a woman living with mental illness. I described the relevance of phenomenology to the study of illness, and the gains that illness can offer to some of its foundational concepts. Phenomenology is particularly well suited to thinking about illness because of its ability to put into question and illuminate the fundamental structures of experience through a form of critical reflection. In describing the difficulties of finding my place in the world, I discussed alternatives to the ideal of seamless body–world compatibility and complicity. Although changes, breakdowns, or disruptions in the course of experience highlight the contingency of embodied experience, they also offer valuable opportunities to transform familiar assumptions and develop new ways of being at home. Moving against the blind assumption that experiences of home and belonging are entirely self-evident, this article has helped to expose the importance of creating a time and place for the experience and expression of disorientations. On this view, embodied changes and acquired sensibilities hold traction in the project of ethical transformation: specific forms of self-awareness and attention *can* transform how we live and care for ourselves, as well as for others. In this process, disorientations and the vulnerabilities that they expose can be reimagined as sites of collective growth and self-transformation.

These transformations, however, can occur only once we recognize the value of experiences of disorientation and our shared ethical responsibility to question their uneven distribution in light of taken-for-granted conditions of experience. The propositions outlined in this article depend on a political desire to recognize human existence as inherently dynamic, vulnerable, and relational. Inasmuch as human experience is characterized by our openness to meaning through the constant ebb and flow of experiences, our dwellings in the world are just as much habitual and fixed as they are permeable and labile. Phenomenological attention to differences in belonging opens the way to new moral responses that are rooted in this recognition and that render livable experiences of serious disorientation. To the contrary, the redaction of these narratives narrows the shape of belonging. The effort and generosity to imagine shared dwellings warrants the careful inclusion of individuals living with mental illness in the articulation of the medical discourses, clinical practices, and social understandings that shape our lives. This project of inclusion further outlines the importance of reforming communal habits and social expectations in ways that recognize differences in practices of home-making. Ultimately, this is both a call to learn from the experiences of individuals living with (mental) illness and an

invitation to expand our understanding of home and belonging based on the insights gained from these narratives.

NOTES

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1. I owe the idea of being in worlds and in-between worlds to Mariana Ortega's exploration of subjectivity as fundamentally *multiplicitous* (Ortega 2016). Ortega's account of existential multiplicity productively complicates traditional phenomenological conceptions of location and identity and allows for an understanding of the ways in which subjects fare in and in-between various (and sometimes conflicting) worlds. I will return to some of Ortega's claims in section III of this article, where I discuss problematic conceptions of "authentic" belonging (Ortega 2016, 197) and being-at-home.

2. Although research on BPD diagnostic biases has focused largely on gender differences, findings also show that racial and ethnic minorities living with mental illness experience increased levels of stigma and discrimination and tend to be perceived as more dangerous (Whaley 1997; Anglin et al. 2006; Wong et al. 2017). Inasmuch as attributions of able-mindedness maintain racial (and other) inequalities and remain tied to their reproduction (Taylor 2015), they expose the contingency of our conceptions of illness and health and the need for a social and medical reconfiguration of the ideal of a "healthy" life.

3. The invisibility of mental illness and other diagnoses and disabilities that are not readily identifiable (for example, chronic pain, rheumatoid arthritis, multiple sclerosis) can create complex paradigms of (self-)identification and stigmatization. Shanna K. Kattari and her colleagues explore some of the ableist microaggressions experienced by individuals living with "invisible" physical disabilities, and the need for a more nuanced understanding of ableist structures and discourses (Kattari et al. 2018).

4. For a discussion of the cultural construction of psychiatric diagnosis, see Gaines 1992. See also Crowe 2000 for an analysis of the normalizing authority of diagnostic criteria, and Lester 2013 for the particular case of BPD. For a phenomenological perspective on psychiatric classification, see Fernandez forthcoming-b.

5. Interestingly, Harbin's account makes room for the idea that receiving a clinical diagnosis can be both orienting and disorienting. Additionally, although they can be disarming or threatening, disorientations are not *always* harmful. As I discuss in section IV, an individual's response to her experience will depend largely on her sensibility, communities of support, and the responses of others.

6. This is also Ahmed's claim in *Queer Phenomenology* (Ahmed 2006). Ahmed argues that orientations are neither casual nor disinterested: they involve social investments in

specific values (for example, whiteness, heterosexuality) and require their reproduction by bodies.

7. These might include experiences of home marked by domestic abuse, manic-depressive illness, intergenerational trauma, state violence, forced migration, refugee status, or facing foreclosure. My hope is that this analysis can point to the pitfalls of an idealized conception of home as well as generate reflection on the experiences that it excludes.

8. In her feminist phenomenological account of home, Luna Dolezal explores foundational and structural aspects of home through an analysis of its gendered dimension (Dolezal 2017). By recognizing pregnant embodiment as our primary dwelling, Dolezal anchors the constitution of bodily subjectivity in the female body's often invisibilized acts of nurturing, sustenance, and care. The first place in which we are held and supported, then, is both materially and metaphorically dependent on (other) female bodies. I am thankful to the anonymous reviewer who suggested this reading to me and reoriented my attention toward the gendered rhetoric of home.

9. See also Gayle Salamon's parsing of the ideal of a maximal grip on the world through her reading of Mary Felstiner's account of life with rheumatoid arthritis (Salamon 2012).

10. Although reflexive self-awareness *can* introduce a beneficial break in the everydayness of existence, it does not always do so. As many have argued, systems of oppression and other forms of inflicted violence, exclusion, and trauma thrust on subjects a form of reflexive awareness that curbs the types of beneficial reflexivity described above (Fanon 1970; Young 2009; Yancy 2016, 2017; Salamon 2018).

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