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What is This?
Tiredness, Fatigue, and Exhaustion in the Context of a Major Depressive Disorder

Caroline Porr,¹ Karin Olson,¹ and Kathleen Hegadoren¹

Abstract

Framed in a multimethod design using ethnoscience and grounded theory, the purpose of this study was to characterize the attributes of tiredness, fatigue, and exhaustion, and to explore their influences on illness experiences in individuals with major depressive disorder. Two domains, mind (attributes: cognitive function, sleep quality, emotional reactivity, social interaction) and body (attributes: stamina and control over body processes), were identified. These attributes changed qualitatively with participants’ progression from tiredness to fatigue and from fatigue to exhaustion, and determined whether participants “faced outward” to engage with others or “faced inward” to protect energy reserves—a decision largely influenced by the capacity “to hold up a mask” to conceal symptoms. The mask was energy depleting, and if participants could not hold up their mask, they withdrew to preserve energy. Findings regarding the role of the mask could contribute to the development of patient self-care strategies and caregiver interventions.

Keywords
depression; ethnoscience; fatigue; grounded theory; illness and disease; social identity

Although we as health professionals are steeped in knowledge about disease, we know much less about illness. This study was part of a larger project on fatigue designed to characterize core attributes of fatigue across ill and nonill populations, and to learn more about the way these attributes influence the experience of illness. The distinction between disease and illness has been delineated by many scholars. For example, Kleinman (1988) defined disease as a maladaptation of biologic or psychophysiological systems, whereas illness is defined by the way disease is experienced in daily life. We adopted the position that the meaning of illness in daily life is derived from the intertwining of one’s own personal and familial situation, the many cultural contexts within which one is embedded, and evolving perceptions and values associated with a given disease state (Kleinman, Eisenberg, & Good, 2006).

The larger research project was also informed by a concept analysis of fatigue. Clarification of the antecedents, attributes, and consequences of fatigue were drawn from the literature, in addition to the second author’s qualitative studies of five populations (Olson, 2007; Olson & Morse, 2005). We selected the five populations—athletes, shift workers, and individuals who have cancer, chronic fatigue syndrome, or major depressive disorder (MDD)—because each is predisposed to fatigue for different reasons. The inclusion of two populations (shift workers and athletes) provided an opportunity to examine the similarities and differences in fatigue in disease and nondisease states. The purpose of this article is to present the detailed findings of a study undertaken with individuals diagnosed with MDD.

A comparison of fatigue manifestation across the five populations led to the identification of two related and significant concepts: tiredness and exhaustion. Descriptions of tiredness, exhaustion, and fatigue are provided in detail elsewhere (Olson, 2007) and are summarized in Table 1. Tiredness was reported by participants in all five study populations as a normal response to activity. The primary features that distinguished fatigue from tiredness were a gradual loss of energy sooner than expected and the onset of anxiety, an inability to concentrate, insufficient sleep, and the propensity to preserve energy for enjoyable or imperative activities. Exhaustion was characterized by a sudden and unexpected loss of energy, confusion resembling delirium, emotional numbness, change in sleep quality, increased drowsiness, and social withdrawal.

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The specific objectives of this study were to describe the attributes of tiredness, fatigue, and exhaustion in MDD, and to outline the process by which these attributes shaped the meaning of illness as it was lived by individuals diagnosed with MDD. For the purposes of this article, we use MDD when referring to the diagnosis of a major depressive disorder, and depressive symptoms when referring to a downturn in mood. Individuals who reported depressive symptoms might eventually have been diagnosed with MDD, but this was not always the case. The word depression sometimes appears in participants’ comments, and within this study was considered synonymous with depressive symptoms. The word energy refers to the total available effort that one is able to access and to exert at any point in time.

Literature Review

Fatigue has been of interest to scientists for more than a century. Fatigue’s complexity makes it difficult to specify exact causal factors (Johnson, 2005). Beard (1869) hypothesized that major underlying mechanisms involve chemical changes in the central nervous system that alter the body’s ability to excrete muscle waste. Researchers led by Grandjean (1968) a century later conceptualized fatigue as a marker for alertness and placed it on a continuum that ran from sleepy at one polar extreme to alert at the other. Most researchers have approached investigation of fatigue from this point of view, with fatigue associated with a wide range of physiological states, chronic medical and neurological illnesses (Lange, Cook, & Natelson, 2005; Piper, 2003), and psychiatric disorders (Addington, Gallo, Ford, & Eaton, 2001; Reuter & Harter, 2004).

A second approach to the study of fatigue, fatigue as a stress response, was based on the work of Bartlett (1953) and Selye (1952, 1956, 1971). From this perspective, fatigue is an indicator that personal resources are overtaxed as a result of undue demands on the body and serve as an early warning signal (Bartley & Chute, 1947). Subsequently, others have posited that fatigue is actually the direct consequence of a faulty alarm system in which the body is alerted too late, at a point when an overexpenditure of energy has already taken place in response to burdening stressors (Swain, 2000). We align with this latter perspective. We conceptualize tiredness, fatigue, and exhaustion as states along a continuum reflecting adaptive capacity. These states are markers for declines in the ability to adapt to stressors. Tiredness is considered a normal response to the stressors of daily life, whereas fatigue is an indicator that one is no longer able to fully adapt to stressors. Exhaustion indicates that one’s adaptive capacity is nearing depletion.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association [APA], 2000), a diagnosis of MDD requires persistent low mood and anhedonia (loss of pleasure/joy in life) plus at least three of seven other somatic symptoms, including fatigue, for more than 2 weeks. Thus, although fatigue is not required for a diagnosis of MDD, it is one of the more common symptoms and is typically the chief complaint prompting individuals eventually diagnosed with MDD to seek medical care (Demyttenaere, De Fruyt, & Stahl, 2005; Johnson, 2005).

Psychiatrists during the 20th Century did not distinguish physiological fatigue from fatigue of a psychogenic origin, and thus considered fatigue and depression to be synonymous. The relationship between fatigue and depression has remained unclear (Torres-Harding & Jason, 2005). Anderson et al. (2003) contended that when fatigue exists along with other depressive symptoms, fatigue is intensified. Addington et al. (2001) employed a prospective population-based design to explore the epidemiology of fatigue in the general population, and to examine the temporal relationship between fatigue and depressive symptoms. Findings suggested that fatigue is both predictive of and a consequence of depressive symptoms. Researchers have noted a strong positive correlation between fatigue and depressive symptoms among those with work-related distress (Long, Hall, Bermback, Jordan, & Patterson, 2008), persons with diseases such as cancer, heart disease, rheumatological disorders (Bardwell, Moore, Ancoli-Israël, & Dimsdale, 2003; Barsevick, Dudley, & Beck, 2006; Lundberg & Rattanasuwanchai, 2007), and hepatitis C virus infection (Treloar & Rhodes, 2009).

Several gaps in the research literature were the impetus for this study. First, we found no studies of fatigue that systematically explored the intersection between illness and disease. As a result, we know little about how fatigue influences the experience or meaning of MDD. Second, with the preeminence of the biomedical model, the etiology of depression as opposed to the psychosocial

| Table 1. Conceptual Definitions of Tiredness, Fatigue, and Exhaustion |
|---------------------------------|----------------|----------------|----------------|
| Concept             | Onset          | Control          | Predominant Characteristics |
| Tiredness       | Gradual, predictable | Body and mind | Muscular, somatic |
| Fatigue          | Gradual, unpredictable | Mind over body | Cognitive, emotional, social |
| Exhaustion     | Sudden, unpredictable | Body over mind | Somatic |
implications of living with depression is allotted greater research emphasis and examination (Wittink, Dahlberg, Biruk, & Barg, 2008). Along the same vein, in most studies of depression associated with chronic disease, researchers have relied on questionnaires to measure context-free depressive symptomatology. Questionnaires such as the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) unveil few insights into the patient’s complex experiential knowledge of depression when compared with information obtained from qualitative clinical interviews. Moreover, despite the growing body of research examining fatigue and depression, there are currently no new learnings derived from inductive studies and the direct accounts of individuals diagnosed with MDD.

Research Questions

The research questions we sought to address were (a) What are the attributes of tiredness, fatigue, and exhaustion from the perspective of individuals with MDD? and (b) How do the attributes of tiredness, fatigue, and exhaustion influence the experience of MDD in daily life?

Method

Design

We employed a multimethod design (Morse, 2003) comprising ethnoscience and grounded theory to address the knowledge gaps identified above. The ethnoscience component provided an opportunity to examine the attributes of tiredness, fatigue, and exhaustion. Rooted in ethnography, ethnoscience is based on the well-established principle that language is the primary symbol system through which meaning is conveyed. Thus, ethnoscience provided a strategy for uncovering meaning reflected in the words participants living with MDD used to describe tiredness, fatigue, and exhaustion (Leininger, 1985; Spradley, 1979). Grounded theory (Glaser, 1978, 1992; Glaser & Strauss, 1967; Glaser, 1992) facilitated understanding of the process participants employed to manage the interface between the attributes of tiredness, fatigue, and exhaustion and the daily illnesses experiences of MDD.

We addressed rigor by means of the verification strategies outlined by Morse, Barrett, Mayan, Olson, and Spiers (2002). These strategies—methodological coherence, appropriateness of the sample, concurrent data collection and analysis, conceptualization, and theoretical development—were integral to the research process and prompted us to modify our approach to ensure that the study outcomes fulfilled the criteria for rigor, especially interpretive and theoretical validity (Onwuegbuzie & Teddlie, 2003). The first strategy, methodological coherence, required that we match the research questions to the appropriate research methods. Because the first research question required a method that would facilitate identification of the attributes of tiredness, fatigue, and exhaustion, we selected ethnoscience. The second research question required a method that would focus our attention on coping strategies and the facilitators and inhibitors of daily functioning and management. With respect to the appropriateness of the sample, we sought individuals who had been diagnosed with MDD and who were able to describe their experiences in sufficient detail for both the ethnoscience and grounded theory components of the study. Data collection and analysis proceeded concurrently. In taking this approach, we were able to use emerging theoretical ideas to shape subsequent sampling and to guide our interview protocol.

Sample

For the results of a qualitative research study to be valid or credible, researchers must ensure that sample participants are able to articulate first-hand experiences of a phenomenon (Morse et al., 2002). Thus, the eligibility criteria for the study included individuals diagnosed by a physician with MDD in accordance with the DSM-IV-TR classification (APA, 2000) and who were under the care of a physician. We excluded individuals if they were suicidal or exhibited psychiatric comorbid conditions (panic disorder, obsessive-compulsive disorder) as identified using the Mini International Neuropsychiatric Interview (MINI; Sheehan et al., 1997).

Twenty-eight individuals expressed interest in the study. All were screened using the MINI (Sheehan et al., 1997). We excluded 13 individuals because of the presence of psychiatric comorbidities, and 1 other following the first interview, as that individual exhibited suicidal tendencies. The study findings are based on interviews with the remaining 14 individuals (7 women, 7 men). The women ranged from 29 to 52 years of age, with a mean age of 39 years, and the men ranged in age from 22 to 63 years, with a mean of 45 years. We collected no other demographic information. All participants were able to speak and read English, resided in a large western Canadian city, and had sufficient energy to participate in a half-hour recruitment interview as well between one and three 90-minute, face-to-face interviews.

Data Collection and Analysis

Following receipt of ethical clearance from the University of Alberta’s Health Research Ethics Board, we recruited through advertisements in community magazines and on
the university radio station, posters on the university campus, and referrals from one of the coauthors, who was conducting a related study. We invited interested individuals to contact the principal investigator by telephone. A member of the research team met with each person to ascertain eligibility and to administer the MINI (Sheehan et al., 1997). Following an opportunity to ask questions about the study, those interested in taking part and who met the inclusion criteria signed a written consent form.

We conducted 24 interviews. We gave participants options in terms of location for the interviews, and most chose to be interviewed in their homes. Fourteen participants were interviewed once. Eight participants who were particularly articulate were selected for second interviews, which included the “card sort” (Spradley, 1979). The card sort is an ethnoscience technique that enables participants to define, categorize, and/or elaborate on terms specific to a phenomenon or topic of research interest. The terms are created by the researcher and/or the participants and placed on cards for selection and exclusion through sorting. Two of the 8 participants were interviewed a third time, during which they were asked to comment about whether or not they agreed with the final results of the card sort. That is, did the descriptors contained in the cards chosen resonate with their experiences of tiredness, fatigue, and exhaustion in the context of a major depressive disorder? Both of the participants strongly supported the final results and thus no further interviews were warranted.

**Ethnoscience phase.**

During this phase our primary objective was to identify the attributes of tiredness, fatigue, and exhaustion. The first interview began with prompts such as, “Please tell me what a typical day is like for you.” Participants were asked to provide examples or recount experiences that would assist the data collector to understand what daily life was like for them. When participants used the word *tiredness*, the interviewer posed probing questions to explore the boundaries of tiredness (e.g., “How is the kind of tiredness you have now similar to or different from the kind of tiredness you had before you were diagnosed with depression?”). Similar probing questions were asked if participants used the words *fatigue* or *exhaustion*, or made reference to the descriptors included in our conceptual definitions of tiredness, fatigue, and exhaustion shown in Table 1. At the conclusion of the first interview, participants were invited to add anything else relevant to the topic that they thought we should know.

Transcripts were reviewed and corrected if required. We then placed words or phrases that fit our conceptual definitions of tiredness, fatigue, and exhaustion (see Table 1), or that were identified by participants as related to their experience of MDD in daily life, on small cards in preparation for the card sort, as defined above (Spradley, 1979). The first participant sorted only the cards from his or her interview, whereas the second participant sorted the cards from his or her interview as well as the first interview, and so forth. Participants were invited to remove a card if it was a duplicate or if it did not apply to them. The member of the research team conducting the interview carefully noted these removals.

Participants sorted the cards three times. In the first sort, participants were asked to create as many piles as they wished, to “think aloud” as they sorted the cards, and to name each pile. They were also asked to discuss similarities and differences between the piles. The cards in each pile were carefully noted, and then they were gathered for the second sort. During the second sort, participants were asked to sort the cards into three piles. As before, they were asked to think aloud as they sorted, to name the piles, and to note similarities and differences between the piles. Following careful notation regarding the cards in each pile, the interviewer gathered the cards for the third sort. This time participants were asked to sort the cards into two piles and, once again, to think aloud as they sorted, to name the piles, and to note similarities and differences between piles. The sorting process was tape recorded and transcribed. We identified relationships between the words on the cards in the first two sorts by treating the piles from the first sort as columns and the piles from the second sort as rows in a table. To include the results of the third sort in the table, we bolded the words that were sorted into the first pile and italicized those sorted into the second pile.

Following a complete review of the transcripts from these sorts, we constructed a taxonomy that reflected the results of all eight participants’ card sorts. The structure of this taxonomy included principle domains at the top, with segregates and subsegregates located beneath each domain (see Table 2). We identified the attributes of fatigue by considering the domains and the segregates. The subsegregates, which were stratified by tiredness, fatigue, and exhaustion, showed how each attribute changed as individuals progressed from tiredness to fatigue and from fatigue to exhaustion.

**Grounded theory phase.**

Our primary objective during this phase was to understand how the attributes of tiredness, fatigue, and exhaustion shaped the experience of MDD in daily life. We analyzed the first and second (card sort) interviews conducted for the ethnoscience phase as they were collected using the constant comparative method (Glaser, 1978, 1998; Glazer, 1992). First, we analyzed the transcripts sentence by sentence for words or phrases that related to living with MDD or to the attributes of tiredness, fatigue,
and exhaustion identified in the ethnoscience component. We then compared these words or phrases one by one with incoming data from subsequent interviews, noting similarities and differences, to create conceptual categories. We identified a core conceptual category that illuminated key issues in the experience of MDD, which served as the referent to the identification of related concepts and coping and management processes. The focus then shifted to relationships between conceptual categories and to the elaboration of conceptual properties and dimensions. Also elucidated were the context, conditions, and consequences of the process by which individuals with MDD responded to the challenges of tiredness, fatigue, and exhaustion in daily life (Glaser, 1978; Glaser & Strauss, 1967).

**Findings**

**Ethnoscience Component**

We identified two domains of fatigue: mind and body. These two domains appear as headings in Table 2. The domain *mind* consists of the segregates of cognitive function, sleep quality, emotional reactivity, and social interaction. Those of the second domain, body, were muscle endurance and control over body processes. The segregates appear in the second row of Table 2. Participants described mind with terms like “mental” and “things that happen in the brain,” whereas body was depicted by words such as “limbs” and “muscles.” The third, fourth, and fifth rows of Table 2 illustrate how the attributes of tiredness, fatigue, and exhaustion form the subsegregates of mind and body.

Participants engaged in an internal dialogue regarding the way in which the mind and the body “managed” fatigue. Most participants could recall a preillness time during which they experienced only tiredness. They characterized tiredness as an effortless interconnection between mind and body. Body and mind seemed to work together with no particular effort consciously required. Fatigue, however, was characterized by “mind over body.” Participants with fatigue reported “pushing myself” and “talking myself into doing” activities that were important. Exhaustion was characterized by “body over mind.” Participants who had experienced exhaustion noted that they had tried to “talk” themselves into doing some activity, as they had before, but it was no longer possible. One woman said, “My body is just doing its own thing and not paying any attention to me anymore.”

As shown by the descriptors provided at the subsegregate level, the segregates changed qualitatively and became progressively more distressing as individuals moved from tiredness to fatigue and from fatigue to exhaustion. For example, the emotional reactivity subsegregates associated with tiredness were “grumpiness” and “frustration.” As individuals moved from tiredness to fatigue, the subsegregates were “anxiety,” “procrastinate,” and “decreased motivation,” and as individuals moved from fatigue to exhaustion, the subsegregate identified was “flat.”

**Grounded Theory Component**

The primary finding of this component of the study was the participants’ experiences of profound disconnection from society and a concomitant inability to fulfill communal expectations regardless of whether they reported tiredness, fatigue, or exhaustion. The perceived disconnection from society accounted for incidents, concerns, and issues that consistently occurred within the participant’s daily life of MDD, and became the core conceptual category that guided the theoretical phase of the study. Participants addressed their sense of disconnection from society through a basic social psychological process that we have labeled renegotiating social roles (see Figure 1 for model). Renegotiating social roles involved implementation of one of two strategies: facing outward or facing inward. These strategies helped participants manage the tiredness, fatigue, and

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**Table 2. Tiredness, Fatigue, Exhaustion Taxonomy**

<table>
<thead>
<tr>
<th>Domains</th>
<th>Mind</th>
<th>Body</th>
</tr>
</thead>
<tbody>
<tr>
<td>Segregates</td>
<td>Concept</td>
<td>Cognitive Function</td>
</tr>
<tr>
<td>Subsegregates</td>
<td>Tiredness</td>
<td>No change</td>
</tr>
<tr>
<td>Fatigue</td>
<td>“Re-hash”</td>
<td>“Stew over things”</td>
</tr>
<tr>
<td></td>
<td>“Stew over things”</td>
<td></td>
</tr>
<tr>
<td>Exhaustion</td>
<td>“Thick and foggy”</td>
<td>Flat affect</td>
</tr>
<tr>
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</table>
exhaustion associated with MDD. The choice to face outward and focus attention on social obligations, or to face inward and to protect energy reserves, was encountered several times over the course of the day. Decisions were driven by the attributes of tiredness, fatigue, and exhaustion. Facing outward occurred mostly when individuals were tired or fatigued, whereas facing inward occurred mostly when individuals were fatigued or exhausted.

When the attributes of tiredness dominated, individuals harnessed sufficient energy to maintain their social commitments and responsibilities. As energy depletion became apparent, participants reported attributes of fatigue and tried to shift their attention to the preservation of energy reserves. During this state, participants gradually moved from facing outward to facing inward, as illustrated in Figure 1. When the attributes of exhaustion prevailed, participants essentially “collapsed,” stating that their “tanks were on empty” and that they had no recourse but to disengage from society so that they could slowly begin to generate energy.

**Renegotiating Social Roles**

**Facing Outward**

Participants employed the strategy of facing outward to enter society and to enact their socially constructed roles. Facing outward was an immense struggle, however, and thus energy reserves were quickly diminished. During this strategy, participants shifted from tiredness to fatigue. Facing outward involved following one of two pathways: disguising depression by entering society with a mask, or going through the motions and entering society without a mask.

**Disguising depression.**

Some participants explained that they were unable to enter society without disguising the signs of depression:

> I suppose we all to a certain degree put on little masks and stuff and then hide who we really are from the outside world, but I definitely, since this depression thing started, and it’s, uh, hard to leave the house without it.

Participants stated that it was critical that coworkers not know the truth about who they really were or how they really felt: “I need to show a particular face to colleagues at work, they expect me to be a certain way.” Home was considered a “safe” place where it was unnecessary to wear the mask:

> So I’d come home Friday night and just stay home, and then Monday morning I’d appear at work,
yes: [sings] La-la-la-la-la. And then I’d come home Friday night and just hobble in, and then appear at work: [sings] La-la-la, you know. [laughs] It was like I was two different people. Or it’s less to cope when I’m home because it’s just me and my own things, and when I’m outside it’s the weather, it’s the noise, it’s the traffic, it’s the people. Um, yes, even just saying hello to people, to strangers on the street, I’m like, “Oh, I don’t feel like doing it because I’m not really happy. I don’t feel like smiling or saying hello, even open my mouth to say one word.”

Thus, home was the place to which participants retreated when they did not have the energy to wear the mask. Before leaving home, participants disclosed that they donned their masks portraying their “happy, pretend face.” This façade enabled participants to project the image of their predepression selves, to be the men and women they used to be:

I don’t think a lot of other people realize that some, a lot of the time, I’m putting on that mask because the mask is so similar to what I was before I got depressed, um and I’m just pulling on those resources.

Disguising depression encompassed three phases: recovering the lost self, conducting self-talk, and enduring depleted energy reserves.

**Recovering the lost self.** The choice to take the pathway disguising depression required that participants first recognize their wish and desire to recover their “lost” self. This lost self was a person who had normal muscle endurance, cognitive function, sleep quality, social interactions, emotional reactivity, and control over body processes. Since their diagnosis, participants had witnessed the loss of connection with friends, the loss of membership in group activities, the loss of involvement in family functions, and the loss of sharing in traditional events and celebrations. Through enactment of their former roles in conjunction with some level of contrived enthusiasm, participants also set out to recoup some measure of the losses incurred since the onset of MDD.

**Conducting self-talk.** Once they had decided to recover their lost self, participants described conducting body-mind self-talk as a means of propelling themselves further within the disguise of their depression:

I train myself, “Okay you’re feeling that way because you’re depressed and just read another page maybe you’ll feel better.” . . . I tell myself, “Oh, just do it,” you know, because its supposed to be good for you then you just do it even though mentally it makes me tired.

Self-talk was an assistive cognitive device that enabled participants to manage their daily struggles with fatigue. Participants repeatedly encouraged themselves through ongoing self-dialogue to “just get up and go” despite the lack of energy. Self-talk, based on self-monitoring and notations of what was deemed beneficial vs. what was considered unhelpful, were widely evident within our data:

I withdraw from people, and I just want to find a barricade and go hibernate until I feel a bit better. . . . And, uh, which is probably the worst thing to do, because, um, what usually helps me feel better is when I’m doing something active and social.

**Enduring depleted energy reserves.** Tremendous energy was consumed by wearing the mask. The resultant state of energy deprivation caused our participants to want nothing more than to “find a cave and crawl in;” “to hide;” and to “shut down.” One participant explained, “I would come home and just crash; it would last two or three days. I would just sit in my room and not leave and not eat and not do anything, just sit.”

**Going through the motions.** Although social roles were at the forefront of their attention, the participants’ performance capability was a moving target as participants could not predict on any given day how they were going to feel in terms of MDD’s debilitating effects. Participants explained that sometimes a “heaviness hit” them first thing in the morning without provocation. They stated that on those days their diminished energy levels were too severe to support the work required to disguise their depression. However, rather than stay home, as one might predict, perceived expectations of colleagues, friends, and family members, and excessive self-demands were key drivers behind the participants’ decision to face outward, despite their lack of energy, and to attend to societal obligations without their masks by going through the motions. Going through the motions comprised engaging mechanically and numbing emotions.

**Engaging mechanically.** Going through the motions required participants to enter society without a mask. One participant described this as “putting in a cameo appearance.” We inferred that participants were capable of only simple, mechanical, detached engagement. They were “just doing what they needed to do,” such as “showing up for work” and “being present” in society:

Or, you know, and a lot of times it wouldn’t be, um, going and sleeping, but it would be just, um, going through the motions. I’d be awake, and I’d be moving around, but [laughs], you know, say, “Well, the wheel is spinning but the gerbil is dead.”
Experiencing numbing emotions. In contrast to disguising depression, participants on this path were not focused on their public face and their projected self. Their affect was flat; they had little energy, and thus energy expenditure was minimal. They were incapable of strategic assessment and deliberation over situational expectations. Participants stated that they would “take an entire weekend and not move” from the couch. One mentioned, “I don’t eat, nothing. I’m just there.” Another participant found reprieve at home, occupying herself with homebound activities:

Well, I don’t drink any coffee, and usually it’s herbal tea. But hiding would be generally just locking myself in the house, and it could mean me laying on the couch all afternoon or all day, or it could mean me sitting down in my work corner, doing some handwork or handcrafts or something like that. But it’s ignoring the phone and ignoring the door and, uh, not worrying about it. It’s harder to do with a husband, because he comes in and interrupts things all the time. But, um, even so, there are days where, while he’s at work, I just hide out. I don’t bother with answering the phone; I don’t bother with doing anything unless I absolutely have to.

Hitting the brick wall: The transition between facing inward and facing outward. As noted previously, facing outward allowed participants to reconnect with society and to fulfill at least some of society’s expectations of them. Once reconnected to society, individuals endeavored to remain in that pattern for as long as possible. Invariably, however, all participants reported hitting the brick wall and needing to completely withdraw from society and face inward. Some participants reached hitting the brick wall from disguising depression, whereas others arrived at this point from going through the motions.

Facing Inward

The nature of MDD was such that participants never knew exactly when facing inward would be necessary. Participants noted that the need to face inward might evolve at the end of the day after engagement in society, or arise suddenly, paralyzing them in their tracks. As such, facing inward fits conceptually on the boundary between fatigue and exhaustion. Participants employed this adaptive process because there were absolutely no energy reserves available. “There is no well to go to. The well is dry.” One participant explained it was analogous to “trying to drive a car with no gas.” Others reported that facing inward was also associated with an onslaught of several depressive symptoms, including overwhelming anger, sadness, discouragement, apathy, despondency, and lack of concentration. One participant noted,

But I just sit there. I’ll sit on my bike for five minutes, and I’ll just know that I can’t leave because I’ll be thinking, “Okay, where am I going? What am I going to do when I get there? And why am I going?” Like, I don’t want to do anything. I know that even if I push myself to go run that errand, it will be an awful experience; I’ll feel terrible. . . . But I’ll just go out and all I will be thinking about is, “How am I going to get home?” . . . Um, I can’t—everything is, it’s internal and it’s like gray fuzzy or fog in my head.

Facing inward comprised two phases: ignoring societal obligations and withdrawing from society.

Ignoring societal obligations. Despite the fact that they acknowledge a disconnection with society, immobilization was certain, and participants were forced to ignore their societal obligations, were resigned to seek social isolation, and were compelled to concentrate on regenerating energy to reenter society. Participants would decisively give themselves permission to forego all commitments:

I’ve just allowed myself to say, “All right, I’m going to cancel today.” I’ll just—you know, that’s it; “I’m canceling the day” . . . That is, I would not allow myself to get down on myself for being down.

In fact, one participant drew parallels between succumbing to the depths of depression and breaking a leg to legitimize his decision to renege on his social engagements:

“You’re depressed. All right, so go lie down . . . If you’ve got a leg—if your leg’s broken, you just can’t dance.” . . . and so I figured, “Right, well, if I’m feeling this bad, well, then, obviously I can’t”—you know, I am not going to go to a party.

Withdrawing from society. Depressive symptoms of apathy and despondency played hand in hand with the listlessness and lethargy induced by energy deprivation. Participants did not have the stamina for activities as simple as taking a shower in the morning: “On the heavy days, when I’ve got to roll out, I could just spend the entire day there [in bed]. I’ll go in the shower and fall asleep in the shower.” Furthermore, participants did not want to put forth an effort. They explained that they had “no desire to do anything.” One remarked, “I would not wanna talk. I don’t wanna think, I don’t wanna write . . . so I’ll sit on
the rocking chair and look out the front window and just like, I’ll be flat. I don’t wanna move.” Any form of social stimulation was particularly burdensome; participants sought to avoid all forms of social interaction:

When I’m in that gray fog, if you don’t wanna be with people, you can’t—you know, like, there’s no social stimulation; you don’t want any of that. You don’t wanna watch TV; you don’t wanna talk; you don’t wanna read; you don’t wanna say anything to anybody.

Some of the participants remained facing inward for long periods of time and were seemingly caught in a luminal space, unable to generate enough energy to do otherwise. However, all participants were able to eventually generate enough energy to deal with the symptoms of MDD and reconnect with society.

Discussion

Participants in this study consistently reported that for them, MDD signified a disconnection from society that was characterized by an inability to experience joy in everyday life and a sense of helplessness and hopelessness. These symptoms created an existential void. This void and the associated feelings of despair and worthlessness, however, were partially lifted when participants felt accepted by society and were able to elicit and sustain ongoing social approval. Social approval, they believed, was earned through their ability to undertake normative social functioning, which encompassed their particular roles and responsibilities.

We became aware that role identity of our participants, not unlike that in the general population (Sullivan, 1953), was a function of interpersonal situations and relationships among family members, friends, and coworkers. Not generalized across populations, however, was the participants’ hypervigilance regarding how others in their social world responded to them. Men and women alike seemed self-conscious about their behaviour, and often deferred to the verbal and nonverbal reactions and responses of others as indicators of whether their own actions and performance were in line with role identity norms. Participants considered themselves competent, productive members of society by virtue of the fact that they were able to merely engage in everyday social functioning, but this perspective was not always shared by those in their social world. Thus, although renegotiating social roles enabled participants to perform activities of daily living and designated duties as expected within their roles as mothers, fathers, husbands, wives, employees, and so forth, and to optimize their sense of self-worth as contributing members of society, it took place in a wider context that was not always supportive.

Noteworthy is our finding that although participants had been socialized to internalize a particular role identity, the process of renegotiating social roles offered participants opportunities for modified roles, roles that they chose for a given moment in time and on their own terms to manage their tiredness, fatigue, or exhaustion. This demonstration of individual discretion is in keeping with the nondeterministic view of behavior that constitutes a tenet of symbolic interactionism (Blumer, 1969). Although symbolic interactionists advocate the critical influence of social interaction on human behavior, they also believe that the self is autonomous, reflexive, and active in determining his or her form of self-expression and role enactment. People do their own evaluating of objects (e.g., environmental pressures, stimuli, motives, and attitudes) as they experience them and act accordingly. An individual engages in dialogue with him- or herself and “selects, checks, suspends, regroups and transforms the meanings in the light of the situation in which he [or she] is placed and the direction of his [or her] action” (Blumer, 1969, p. 5).

Nine participants either had no children or were parents of grown children, and thus we were not surprised that they identified home as a place that afforded a quiet and private retreat. The limited sociality of the home setting was analogous to the backstage of a theatrical play where participants went to conceal their melancholy and lethargy, and prepared with fine clothes, makeup, hair-styling, proper facial expressions, and preferred mood for the “front stage self” (Goffman, 1963). By means of this theoretical mask, participants were able to present and maintain a consistent face and assume socially appropriate attitudes and responses that were repeatedly reinforced and rewarded in social settings such as the workplace. Wearing the mask, combined with contrived gaiety and cheerfulness, replaced all signs of detachment attributed to depression, enabling participants to once again perform to some extent both essential (vocation) and discretionary (leisure) activities, and thus partially regain some of the losses they attributed to MDD.

Five study participants (3 women, 2 men) had young children. The women reflected on the impact of their depression on their children, but the men did not discuss nor share this sentiment. One woman lived with her parents and noted that as grandparents they assumed many of the child care responsibilities, as she was often unable to participate in family activities because of her depression. This participant did not wear her mask at home, and consequently her children were exposed to their mother’s illness on both the “good” days and the “bad” days. In contrast,
the two women remaining, who were divorced and shared child custody, indicated that they put on their “brave face” and “faked it” with their children on the bad days. These early findings suggest that for some parents with young children, home might not afford a quiet place within which to restore energy and to make the transition back from exhaustion to fatigue or tiredness, to resume societal obligations through fulfilling external role expectations.

Personal agency and other opportunities to take control over one’s life are major contributors to health and well-being (Marmot, 2004). This raises questions about the extent to which the act of choosing, particularly in this study, might actually generate energy, which can then be reinvested in continuing to remain connected with society, despite the inordinate effort required, given the nature of MDD. One participant had chosen to no longer hide her depression, and to move beyond engaging mechanically and numbing her emotions. She noted that she was becoming increasingly comfortable with simply being herself in society. She said she had been depressed since childhood, but wanted to become the person she would otherwise have been. She had become less concerned about society’s expectations of her and had found new ways to contribute to society that were already providing rewarding feedback. As she was the only participant who reported this phenomenon, it is difficult to know whether this was the beginning of another stage in the management of MDD, but given the potential for hope that it offered, additional research is warranted.

Unfortunately, more often than not persistent negative thinking, coupled with the debilitating weariness of fatigue, jeopardized the capacity of participants to meet societal obligations. Even on those occasions when participants demonstrated psychological fortitude and required little inducement, they reported that it was the reduced motivation that sabotaged daily social integration and successful performance. Participants explained, “It’s not that I don’t want to, it’s that I can’t. There’s nothing.” Similarly, “The heart and brain say one thing and the body says no.”

As noted previously, this study was part of a larger project in which we compared fatigue as it occurred in five populations who experienced it for different reasons. These populations included individuals with cancer, MDD, or chronic fatigue syndrome, or individuals who were shift workers or recreational runners. Our studies of these populations culminated in the construction of the Edmonton Fatigue Framework (EFF). In the EFF we proposed that fatigue is a behavioral marker for the lack of adaptive capacity with respect to stressors, and that this lack of capacity is a function of the combined effects of declines in muscle endurance, sleep quality, cognition, dietary intake, and social interaction, and an increase in emotional reactivity. Within our other project populations, the lack of capacity was triggered by disease processes (cancer or chronic fatigue syndrome), or other kinds of activities (shift work or recreational running) that were highly structured and competitive, and the progression from tiredness to fatigue was readily apparent (Olson et al., 2007). As shown in Table 2, the study participants, all of whom had MDD, reported significant fatigue, as defined in Table 1, and shifts in muscle endurance, sleep quality, cognition, dietary intake, social interaction, and emotional reactivity that were similar to our other populations. Some could recall aspects of their lives prior to their MDD diagnosis that were more consistent with our definition of tiredness.

An interesting paradox in this study not witnessed among the other populations was that participants consistently reported feeling “better” while they were immersed in social interaction, with or without their masks. That is, although interaction in society required the expenditure of energy, participants claimed that their “spirits were lifted” and thus viewed their efforts as worthwhile. The challenge, then, of MDD, is that the immense energy required to reconnect with society cannot be sustained indefinitely, despite tremendous benefits, and thus demands periods of withdrawal to restore precious energy lost.

Our findings raise many questions about possible interventions. How might one intervene so as to increase adaptive capacity in individuals with MDD? How could one support individuals with MDD who would like to attempt facing outward without their mask? How might one support individuals who have no home or safe place to which they can retreat to regenerate their energy? We are currently working on these questions with frontline practitioners in rural and urban settings, and are looking forward to the opportunities that these collaborations will afford with respect to knowledge translation, improved clinical outcomes, and future research.

Conclusions

In our study individuals with MDD were plagued on a daily basis by the struggle to remain connected within their social world in some meaningful way. Although the attributes of fatigue were most commonly reported by our participants, they also experienced tiredness and exhaustion. Progress toward reconnection was easiest when participants were experiencing tiredness, but became progressively more taxing as they transitioned from tiredness to fatigue and from fatigue to exhaustion. The two strategies implemented to promote reconnection, wearing a mask and not wearing a mask, required varying levels of energy and were likely significant contributors to the fatigue experienced by participants. To renew their energy reserves, participants found it necessary to periodically withdraw from society.
The accounts provided by the study participants illuminate understanding of the daily illness experiences of individuals diagnosed with MDD. These new insights, building on the work of Kleinman and colleagues (2006) in conjunction with what we already know about the physiological aspects of this common chronic disease, will equip care providers with a broader foundation upon which to develop initiatives to assist patients to manage MDD.

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