Dual, Yet Dueling Illnesses: Multiple Chronic Illness Experience at Midlife

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Abstract

The prevalence of multiple chronic illnesses is increasing dramatically, especially among those in middle adulthood, yet much prior research has focused on the experience of multiple morbidity among older adults. We examined the online illness narratives (blogs) of 10 men and women aged 36 to 59 to better understand the experience of living with multiple chronic illnesses at midlife. Multiple morbidity presents distinct challenges to those at midlife: (a) diagnosis and management of multiple illnesses, (b) need for information, (c) identity dilemmas and threats to self-image, and (d) stigma and social rejection. Relinquishing the work identity was especially difficult for participants because it threatened to foreshorten middle adulthood and push them prematurely into late adulthood. Participants used their blogs to revise their identities, alleviate isolation, and inform and guide others.

Chronic illnesses have largely replaced infectious diseases as the leading cause of death and disability worldwide. The World Health Organization (WHO; 2013) estimates that 60% of deaths worldwide are attributable to chronic disease. Long a problem in high-income nations, chronic disease has become a global threat with 80% of chronic disease deaths occurring in middle- and low-income nations (WHO, 2013). In the United States, it is estimated that one out of every two adults has at least one chronic illness (Centers for Disease Control and Prevention, 2013).

The number of individuals living with multiple chronic illnesses is increasing dramatically: In 2010, 26% of American adults had two or more chronic illnesses compared with 21.8% in 2001 (Ward & Schiller, 2013). Individuals with multiple morbidity are at greater risk of being diagnosed with additional illnesses and are more susceptible to complications from treatment (Boyd & Fortin, 2010). Although 65% of Americans covered by Medicare (the national health insurance program for elderly citizens) have more than one chronic illness (Wolff, Starfield, & Anderson, 2002), the problem is not confined to older adults; Hoffman, Rice, and Sung (1996) estimate that 51% of middle-aged adults have multiple chronic illnesses.

Chronic illness requires a focus on management and care as opposed to treatment and cure. The physician's role in the management of chronic illness diminishes, supplanted by other health care providers and family members, as well as the patient himself or herself. Accordingly, the management of multiple chronic illnesses becomes increasingly complicated. Although there is an established tradition of research on the experiences of individuals with a single chronic illness (e.g., Charmaz, 1983; Kleinman, 1988; Strauss & Glaser, 1975), less is known about the experiences of those with multiple morbidity. Researchers have found those with multiple chronic illnesses develop various coping strategies (Hurd Clarke & Bennett, 2013; Roberto, Gigliotti, & Husser, 2005), benefit from social support (Lowe & McBride-Henry, 2012; Roberto et al., 2005), and have difficulty managing treatments for multiple illnesses (Fried, McGraw, Agostini, & Tinetti, 2008; Lindsay, 2009). Research indicates those with multiple chronic illnesses tend to suffer from depression (Lindsay, 2009; Schoenberg, Bardach, Manchikanti, & Goodenow, 2011), receive poor continuity of care, and experience negative interactions with health care providers (Williams, Dunning, & Manias, 2007).

Most of the previous research on multiple morbidity focuses on older adults and suggests that chronic illness is an anticipated part of the aging process. However, a significant and growing number of middle-aged adults are

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diagnosed with multiple morbidity, and it is likely that they experience multiple morbidity differently. To more effectively and efficiently care for patients with multiple morbidity, it is necessary to better understand the experience of living with multiple chronic illnesses, especially for those with longer life expectancies. The purpose of this article is to examine the illness narratives of middle-aged men and women with multiple morbidity to expand our understanding of the social consequences of having multiple chronic illnesses at midlife.

Theoretical Perspective

Our analysis of these illness narratives is informed by Strauss and Glaser's framework of chronic illness and Bury's concept of biographical disruption. Strauss and Glaser (1975) examined the social and psychological dimensions of living with chronic illness and revealed multiple problems including the prevention and management of medical crises, controlling symptoms, maintaining regimens, social isolation, uncertain disease trajectories, attempts at normalization, and financial issues. Bury (1982) noted that chronic illness encompasses three types of disruption: (a) the disruption of taken-for-granted assumptions and behaviors; (b) disruptions in explanatory systems necessitating biographical revision; and (c) the need to respond to disruption, which requires mobilization of resources. Bury pointed out that age is a significant factor in the experience of chronic illness because it "mark[s] a biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging" (p. 171).

Illness Narratives and the Experience of Illness

Illness narratives are distinctly social because they connect the individual to society (Hunt, 2000). Garro and Mattingly (2000) described narrative as a "mode of thinking that marries singular circumstances with shared expectations and understandings acquired through participation in a specific culture" (p. 24). Similarly, Bochner (2001) explained that individuals derive meaning from their illness by negotiating between culturally dominant illness scripts and their situated understanding of their own experience. According to Docherty and McDoll (2003), not only do authors of illness narratives desire to be heard and understood, but they are also seeking validation for their interpretation of the experience. They share their experiences in anticipation that others will learn from them (Frank, 1995). Skultans (2000) explained that illness narratives produce both self-awareness and awareness of others, "because in recognizing the vulnerability of others we

recognize our own" (p. 8). Illness narratives can also be used to express resistance to the power and hierarchy structures within the social institution of medicine (Mishler, 2005).

Thorne and Paterson (1998) reported that representations of the chronic illness experience have changed considerably over the last several decades. In the 1980s, chronic illness research had an outsider perspective and depictions of the experience focused on loss, pain, and suffering. However, since the 1990s, representations of the chronic illness experience increasingly have an insider perspective and are more positive, focusing on empowerment, self-discovery, and transformation, thereby constructing an "idealized chronically ill person as strong, powerful, and competent—misrepresenting the complexity of the phenomenon" (Thorne & Paterson, 1998, p. 176).

This shift in perspective has given rise to a debate regarding the authenticity of "the patient's voice" and the validity of research findings derived from illness narratives. Atkinson (1997) initiated the debate with his critique of Frank (1995), Kleinman (1988), and Mishler (1984), arguing that the authenticity of research participants' perceptions and feelings has been overstated. Atkinson characterized research studies based on illness narratives as "romantic celebration[s] of the individual subject" (p. 335) because of their tendency to focus on patient empowerment and self-discovery. According to Atkinson, illness narratives are too often under-analyzed by "semischolars" who neglect to address the social context in which the narratives were created. Atkinson argued that more attention should be paid to the social constructedness, performative nature, and function of illness narratives.

Bury (2001) acknowledged that illness narratives are performative and serve many purposes but asserted that the patient's perspective is important, because it represents an alternative source of knowledge, one that has until recently been discounted. However, Bury argued that illness narratives need to be contextualized, interpreted, and evaluated, instead of taken solely at face value. Miczo (2003) questioned the accuracy of patient narratives, suggesting that researchers might be engaging in a "fetishism of words," treating words as "real entities that stand for the experiences they represent" (p. 469). He characterized narrative as "motivated biographical work" and encouraged researchers to attend to its performative function. Bochner (2001) argued that the purpose of narrative is to convey the significance and meaning of an experience, not just the facts of it. According to Bochner, "narrative is our means of recollecting the meanings of past experiences, turning life into language, and disclosing to us the truth in our experiences" (p. 154).

Thomas' (2010) analysis of the debate led her to conclude that illness narratives are "*socially constructed* accounts that express the *meanings* that *real* events and social circumstances have [emphasis in original]" for their authors (p. 656). They are social performances, which are no more authentic, objective, or valid than other types of rigorously generated data. In this article, we took a position similar to that of Thomas. We viewed the narratives as constructed accounts, reflecting the social realities of their authors, written by them as a means of organizing and assigning meaning to their experience. The narratives provide an important perspective and source of knowledge about living with multiple chronic illnesses in midlife.

Method

Data for this article came from online illness narratives, in the form of diary blogs. Blogs originated around 1995 by programmers posting on their individual websites, and by 1997 had become widespread once software companies began providing templates requiring no programming or web design skills (Serfaty, 2004). There are many professional journalists who blog about news and politics, although two thirds of American bloggers are "hobbyists" (Sobal, 2010), for whom online diaries are the most popular form (Hookway, 2008). Blogs are a unique form of illness narrative in that they contain extensive accounts of contextualized experience. Authors post entries regularly for periods that often span many years. Many blogs allow reader comments; this potential for dialogue is one of the main differences between online and traditional illness narratives (Hookway, 2008).

Online illness narratives are increasingly utilized as sources for social science research on medical issues (e.g., Armstrong, Koteyko, & Powell, 2011; Furness & Garrud, 2010). They offer data in an easily accessible naturalistic form. Without interviewer influence, the narrator controls the content of the story, addressing the issues that most concern him or her (O'Brien & Clark, 2012). Because the narrative is situated in the present, authors of online illness narratives are "doing their illness here and now" (Seale, Charteris-Black, MacFarlane, & McPherson, 2010, p. 600). The temporal format of blogs allows researchers to study social processes over time and minimizes the telescoping phenomenon associated with a retrospective design (Furness & Garrud, 2010).

Sample

Numerous blogs detail the experience of living with chronic illness, yet far fewer detail the experience of living with multiple chronic illnesses. Our sample consisted of blogs that (a) were authored by individuals with at least two chronic illnesses, (b) were publicly accessible without subscription or login, and (c) contained substantive content about the illness experience through regular postings over a period greater than 1 year. We followed the U.S. Department of Health and Human Services' (2010) definition of chronic illnesses as "conditions that last a year or more and require ongoing medical attention and/or limit activities of daily living" (p. 2). We used multiple search engines and multiple search terms to find blogs meeting these criteria, viewing 122 blogs. Our intent was to identify as many blogs as possible; however, only 10 met the above criteria at the time of our search.

The blogs were written by men and women diagnosed with various combinations of chronic illnesses whose ages ranged from 36 to 52 when they began their narratives. Nine of the authors were American and one was Canadian. Their chronic illnesses included multiple sclerosis (MS), rheumatoid arthritis, chronic obstructive pulmonary disease (COPD), fibromyalgia, congestive heart failure, lupus, Lyme disease, HIV/AIDS, diabetes, amyotrophic lateral sclerosis (ALS), and cancer. At the time of our analysis, at least half the sample had posted to their blog for 2 years, whereas two authors had posted for 6 years, and one for 7. The shortest length of time covered was 14 months. Most authors posted daily or every other day, with some lapses during times of medical crisis. On average, the posts were several paragraphs long, but often they were much longer, depending on the topic. Many of the blogs contained photos, links to other sites, and comments from readers, but we did not include these in our analysis.

Ethical Issues

Using online illness narratives for research raises two issues regarding the use of human subjects: informed consent and anonymity. Several researchers (Hookway, 2008; O'Brien & Clark, 2012; Pitts, 2004) have asserted that material posted online not requiring subscription or password access is intended to be public and therefore does not require consent. O'Brien and Clark (2012) and Pitts (2004) argued that publicly accessible online material which is presented as published creative work intended for an audience should not be subjected to anonymity, but should be properly credited; doing otherwise could be viewed as copyright infringement. Bruckman (2002) characterized such material as "semi-published" work created by "amateur artists." To address this dilemma between protecting vulnerable human subjects and crediting their creative and intellectual work, Bruckman suggested a continuum of positions from "no disguise" to "heavy disguise." We took a position of "moderate disguise"; we did not refer to the authors by their blog usernames and we took care not to include

identifying information in quotations. We received approval for the research from our university's Institutional Review Board.

Data Analysis

For this article, we used the preliminary phase of grounded theory methods, open coding, which consists of a line-by-line analysis of the text. Concepts were identified by indicators (words or series of words) that were subjected to constant comparison until the concept was narrowly defined (LaRossa, 2005). We coded the blogs independently, breaking the text down into concepts and generating analytic memos in which we noted the emergence of new codes or conceptualization issues. These memos formed the basis of regular meetings during which we compared coding, resolved ambiguities, further refined coding categories, and grouped codes into higher-level conceptual categories.

Findings

Diagnosis and Management of Multiple Illnesses

As Bury (1982) pointed out, chronic illnesses do not "break-out," rather, their onset is insidious, as symptoms "creep-up" until they demand attention. Diagnosis often entails a series of false starts and dead ends, with considerable time spent in "diagnostic limbo" (Corbin & Strauss, 1988). The process is even more problematic for those with multiple illnesses because the symptoms of one illness complicate the diagnosis of another. Just getting diagnosed was an ordeal for these authors: Their symptoms were contested and they were misdiagnosed. It took one author 4 months to convince her doctors she was seriously ill, and another spent 8 years "in limbo." Yet another author, forced to move back to the town she grew up in so her parents could help her, worried that her new doctors would think she was "faking."

Desperate for answers, one author posted a photo on his blog of a suspicious rash—which a reader identified as a symptom of Lyme disease, facilitating a diagnosis after 3 years of having symptoms his doctor minimized as "rare." Similarly, another author was misdiagnosed with Type 2 diabetes and correctly diagnosed with Type 1 diabetes a year later when one of her "Twitter friends" said her story sounded familiar and insisted she see an endocrinologist immediately. Yet another author described her experience:

> Had I listened to that first doctor, my life would have been very brief. I wasn't just "working wife and mother syndrome" tired, I was in immediate danger of dying. In defiance of my

loyalty to Dr. C, I went to a rheumatologist even though my doing so made my "dear" family doctor angry . . . I defied my once-cherished family doctor and that was the first step I took to save my own life.

She was patronized by her physician who feminized her symptoms and failed to take them seriously, putting her in grave danger. Her anger enabled her to challenge her physician's authority, ending a relationship that she had previously experienced as satisfactory, as long as she remained in her place within the doctor–patient relationship. This author believed she would have died had she not stood up for herself.

The appearance of new symptoms brought about confusion and frustration regarding their meaning and significance. It was imperative that the authors assign symptoms to the appropriate illness to ascertain their implications, although this was nearly impossible for them to do. Certain illnesses and treatments exacerbated others, and as some authors believed, contributed to their etiology. As one author described,

> The treatments for [lupus] can (and in my case did) cause cancer . . . There are so many complications . . . I have to go off x med for x amount of time. But it complicates y disease. Which in turn flares z . . . What is happening in my throat and thyroid and esophagus is a clusterfuckery from the Crohn's disease they are concerned that I have.

This author's post illustrates the interactive effects of her illnesses and their treatments, as well as the difficulty in diagnosing new conditions and developing a treatment plan that takes them all into account. The authors saw multiple physicians who were specialists in one disease but knew nothing about the other, and failed to communicate with one another. Some authors had illnesses that precluded treatment for other conditions; for example, one author's congestive heart failure rendered his brain tumor inoperable. Another author expressed her skepticism about successful treatment:

> What could possibly be the prognosis for someone with both Lupus and Hodgkin's, diseases which would battle one another and void all the most powerful cancer fighting weapons? I realized what that meant—that I had two diseases whose treatments could not be tolerated in tandem. Unless a miracle intervened, I was doomed.

Her post foretold a story of two illnesses in conflict with one another, dual, yet dueling illnesses.

The authors received a serious blow when diagnosed with another illness. They considered themselves relatively young, and their additional illness was unanticipated. Their once taken-for-granted futures became uncertain. Plans and goals might never be realized, as one

author acknowledged in his post: "My life, my dreams, my hopes, are now gone, up in a puff of smoke." Common concerns included the ability to continue working, anticipation of increased physical limitations, potential ramifications of relationships, and especially, fear of premature aging.

Need for Information

Their additional diagnosis sparked an immediate quest for knowledge, what Corbin and Strauss (1988) termed "information work"; however, these authors could not get the information they sought from their physicians. As one author wrote,

> When I was first diagnosed with diabetes, I knew NOTHING. It was frightening, overwhelming and I was angry that more information wasn't available to me. My Dr. had told me to search the web, but make sure I only look at well-known medical sites like the Mayo Clinic, etc. I did that. I quickly learned a lot about my body, and Diabetes. But, it was missing personal experience. The Mayo Clinic website didn't tell me anything about what "high" felt like, or what to expect on a personal level . . . These were the details that my Dr. couldn't tell me. These were the real, day-to-day experiences that would help me make decisions in the future . . . The information I searched and searched for was nowhere to be found.

Desperate for knowledge, this author was left to find it on her own. However, the information she found was insufficient to answer her most pressing question: What does this diagnosis mean for me? She felt afraid, angry, and frustrated. Their experiences with missed or incorrect diagnoses led many authors to conclude their doctors lacked the requisite knowledge to treat them successfully. One author wrote, "It was like seeing the guy who graduated last in his class from medical school." Many of the authors had similar experiences, making them feel they had to take matters into their own hands.

These authors became experts on their diseases. With this assumption of responsibility came some sense of power and control, as one author wrote, "I am the ringmaster of my own three-ring circus." This sense of power and control was illusory; at any moment, a flare-up or acute incident could render them dependent on medical care. The nature of their chronic illnesses caused them to experience what Alexander (1982) referred to as "biphasic alternation of control." When their conditions were stable, their care was their responsibility, but when their conditions deteriorated, responsibility for their care reverted to medical professionals. This compulsory relinquishment of control induced guilt and confusion about their ability to manage their diseases.

Identity Dilemmas and Threats to Self-Image

Those with chronic illness suffer what Charmaz (1983) described as "a crumbling away of their former self-images" (p. 168). Identities that were sources of pride for these authors, such as artist or athlete, were overshadowed or replaced by identities perceived as negative, such as disabled, chronically ill, old, "professional patient." Their illness identity was inconsistent with their self-image, and was therefore rejected, as one author put it, "We are not our sickness." Another author claimed that "a fatal illness does not change who we are . . . None of us want to be identified as the illness we have"; indicating her illness identity was such a threat to her self-image that she denied its impact, insisting that she was unchanged by her illness experience.

It was especially difficult for these middle-aged authors to forfeit their work identity at this stage of their lives. One author considered work "the last piece of my 'normal life' I had held onto and I was now letting go." Although another author qualified for disability status, he refused it, as he wrote, "When I quit working I want it to be because I retire . . . not because I can't." It was difficult for these formerly able-bodied authors to conceive of themselves as disabled, and that, as one wrote, "Returning to work is never going to be an option." Another author described his experience at a clinic:

> The attendant/nurse had to ask questions for their questionnaire. One of the questions was "are you working?" Instead of just asking me that she went to "working, oh of course you are, you're too young not to be" to which I had to say, "no, I am on disability."

This passage illustrates the cultural importance ascribed to working. Even a medical professional in a clinic assumed that this author would be working because of his age. To account for not working, he was obliged to publicly claim the label "disabled," in effect disclosing his reduced social status. These authors' work identity was an important component of their self-image; it signified that they were independent, productive, and therefore valued members of society. Relinquishing their work identity was an especially distressing biographical disruption that shattered their illusion of stasis, evoking the specter of a future diminished by illness and early aging.

Their blogs were a means of identity work, through which many of the authors were able to establish a new and worthy self-image. As a result of their own quest for knowledge and their experience, they had assembled personal collections of information containing medical and social information unavailable elsewhere. By virtue of their specialized knowledge, these authors had become a much-needed resource for others.

Stigma and Social Rejection

Most of the authors experienced a significant amount of stigma. For some, stigma accrued to the illnesses themselves; for example, HIV/AIDS, lung cancer, and diabetes are seen as diseases brought on by one's own poor choices. Others experienced stigma as a result of visible medical apparatuses or equipment. Physical impairments, surgical deformities, and conspicuous symptoms also drew negative attention from strangers. One author found herself stigmatized not only by friends and acquaintances who saw her as "polluted and polluting" but also by members of the medical community "who glance fleetingly at my blood work and are AFRAID to touch me."

Their stigmatizing experiences frequently led to isolation. One author, embarrassed by his appearance, no longer ventured into public, preferring to live "under voluntary house arrest." Others found they had become persona non grata as friends and acquaintances gradually or sometimes abruptly ceased contact. Another author wrote,

> Those who used to be our friends and even family stop calling. Not even returning our calls. Time passes and people are forgotten. I truly do not get this! It is not like we have some contagious disease that passes through the phone! Are people really this ignorant and uncaring after being close for so long? Yet it still saddens me when those I care about cease to exist.

This author expressed her pain, anger, and even sense of betrayal at being cut off without notice or explanation by those with whom she had long-term close relationships, and especially those whom one should be able to count on, "family." She insisted there was no legitimate reason for such abandonment.

As the blogs progressed, it became evident that the daily management of their chronic illnesses began to consume increasing amounts of the authors' time. They needed to talk about their experiences and feelings, but found that once they mentioned their symptoms, treatments, or fears, conversations ended and people took their leave. There was a limit to the amount of illness talk their friends and family members could listen to, before they turned off and turned away. As one author described,

> I struggle NOT to discuss my health outside my support groups and doctors . . . because people don't WANT to hear it. They get queasy and feel strange. I watch their faces cringe up . . . I am now just "the sick." It is as though I am now invisible . . . And I realize I have become that space where we relegate sick people—we put them someplace where they do not pollute us.

As this post illustrates, the authors learned that they had to carefully consider how much to reveal about their illnesses to minimize the risk of social rejection. Blogging enabled them to communicate the entirety of their illness experience.

Although many had supportive spouses or partners, some of the authors derived immense emotional support from blogging. As one author explained,

> I don't think you can understand the depth, the reality of these cyber relationships. The bonds of loving support that develop as we accompany each other on this leg of life's journey. The degree of comfort and support given and received is beyond measure.

Their blogs provided a platform for uncensored disclosure and the acceptance and support of interested others, mitigating much of the isolation these authors suffered.

Positive Thinking and Hope

A few authors made an effort to frame their illness experience in a positive way. One author began his blog with the intent of "thinking positive," and although he professed to "look on the sunny side of life," his posts oscillated between hope and despair. Another author admitted to indulging in an occasional "pity party," but they were "parties for one" as he tried to "put on a good face" for the rest of the world. Others were not at all positive and made no apologies for it. Many had also been diagnosed with depression at one time or another and two had experienced a hopelessness so vast that they had at one point considered ending their lives. One author, who described herself as "broken in spirit," countered the focusing on the positive rhetoric by arguing that although she had developed the ability to give others information and advice, it was "NOT a blessing."

Another author, however, suggested there might be some recompense for her physical losses: "Where once I had the great physical strength of superwoman, I now have the great mental strength of Anne Frank to make every day count." Invoking the metaphor of Anne Frank indicates that her experience has given her the courage to endure adversity and hope for survival in the face of an uncertain future.

One author offered an even broader perspective in this post written shortly before her death:

> I want to keep my eyes wide open to what the future holds. . . . Illness confronts us with some of the greatest uncertainties we ever face. In my case—and really for all of us—the uncertainty is not about what the future holds, but how it will unfold. . . . As I'm less able to get around, I notice a lot of things through the front window of our house: hummingbirds, the clouds in the sky, the quality of the light. In the right frame of mind, I draw from these things the sense

of the transcendent, of the reference everywhere to God. They enable me to sense in small things the beginning of infinite significance.

This author explained that because we all face a similar fate, our uncertainty about the future concerns not "what the future holds" (ultimately death) but "how it will unfold," or what we will experience in the meantime. Her life had constricted as a result of her limited mobility, yet also expanded, as she described an awareness of things previously unnoticed. Attending to such things as hummingbirds and clouds enabled her to engage with the wider world via nature and spirituality. This author's post reveals a conceptualization of hope that moves beyond the expectation of a particular outcome to a transcendent awareness of life and possibility (Agich, 1995), although, her phrase "in the right frame of mind" indicates that this is perhaps a transitory state. In addition, in another post, she emphasized that her illness was not a gift "and don't let anyone suggest to you that it is."

Discussion

The authors in this article experienced the problems Strauss and Glaser (1975) identified, but also suffered from additional problems that fall into the following categories: (a) diagnosis and management of multiple illnesses, (b) need for information, (c) identity dilemmas and threats to self-image, and (d) stigma and social rejection. Diagnosis and management of multiple illnesses were significant problems. Having a prior condition made diagnosis of a subsequent illness much more difficult. The authors were unsure whether new symptoms corresponded to an existing condition or whether they indicated something else. Some conditions had overlapping symptoms, especially those diagnosed through exclusion (Jutel, 2011).

Those suffering from contested diseases, such as chronic fatigue syndrome and fibromyalgia, often find their credibility and integrity threatened throughout the lengthy diagnostic process (Thorne, 1993). Although such a diagnosis might bring relief with its legitimation of symptoms (Jutel, 2011), many of these authors were compelled to keep their diagnosis a secret to avoid stigmatization. Diagnostic uncertainty or having to defend the legitimacy of symptoms increases distress and causes dissatisfaction with the medical profession (Nettleton, 2006). Being diagnosed with an additional chronic illness at a relatively young age meant that these authors would have to manage yet another illness for many years.

An existing illness not only makes subsequent diagnoses difficult but also complicates the management of each illness. Symptoms, medications, and treatments might have interactive effects or unintended consequences. For these authors, one illness or its treatment exacerbated another, or treatment for one disease was contraindicated because of its effect on the other. Often, desirable outcomes are not achievable for all illnesses and patients and their physicians must consider potential tradeoffs among outcomes (Fried et al., 2008).

These authors were treated by multiple physicians, specialists for one illness who knew little about the other illnesses and, like others with multiple illnesses, perceived their care to be fragmented and incomplete (Boyd & Fortin, 2010; Thorne, 1993). Much of their time was spent in doctors' offices and treatment facilities and their interactions with health care providers were often unsatisfactory. The authors were affected financially to varying degrees; one author without health insurance regularly went without medication because of lack of funds.

Because of the interactive nature of their illnesses, and their past experience, many of the authors developed complex self-management regimens. Often these regimens conflicted with their physicians' recommendations but seemed to be effective (Schoenberg et al., 2011). Depending on the confluence of symptoms, at times the management of one illness became urgent while the other temporarily receded into the background, allowing (or requiring) the authors to prioritize one over another. As these narratives illustrate, the management of multiple chronic illnesses "is a complex task that defies extrapolation from single-disease self-management studies" (Schoenberg et al., 2011, p. 608).

A second problem area for these authors was the lack of information about their newly diagnosed illness. Dissatisfied with the information made available to them by their providers, they turned to Internet sources. The layperson's access to professional medical information has vastly expanded with the recent explosion of websites devoted to health issues. Patients seek information to compensate for their lack of confidence in their providers (Asbring & Närvänen, 2002), and to get a better understanding of how their illness might affect them personally.

These authors considered their online medical research crucially important, possibly even key to their survival (Pitts, 2004). They sought information about illness trajectories and details about specific procedures, topics patients find especially troubling (Mishler, 2005; Strauss & Glaser, 1975). Access to information from both orthodox and alternative sources gave them a sense of power (Asbring & Närvänen, 2002; Jutel, 2011), enabling them to take a more active role in their treatment. For many of these authors, gaining medical knowledge was an adversarial process, as Pitts (2004) reported demystifying medical expertise can be perceived as an attempt at reducing the power differential between physician and patient.

The authors of these blogs came to consider themselves medical experts, and sharing their specialized knowledge positively affected their self-image. However, it takes time and skill to find, interpret, and apply such medical information. The amount of material available online is overwhelming and "dangerously confusing" (Varul, 2010). It can be difficult for the average layperson to discern the reliability of Internet sources. The middle-aged authors in this study engaged in significant amounts of "information work," a finding missing from studies of older patients with chronic illness.

Identity dilemmas and their effect on self-image created a third problem area for this group of authors. Their experience of multiple chronic illnesses necessitated the relinquishment of prior identities, the addition of new ones, and changes in the salience of those remaining. Re-assembling their identities and amending their self-image were considerable challenges because middle-aged chronically ill people have more difficulty dealing with identity issues than those who are older (Charmaz, 1994). The loss of the work identity was especially troubling for these authors because it occurred at a point in their lives where they were advancing in their careers. Given the cultural importance of work, its relinquishment signified the loss of independence and self-sufficiency. Their unanticipated job loss also thrust these authors into the category of "disabled," a label most were reluctant to accept. For those who are chronically ill, continued employment is associated with higher quality of life (Aronson, 1997), whereas involuntary unemployment negatively affects relationships, health, self-worth, and credibility (Bradley et al., 2004).

The loss of the work identity and its association with disability propel those with chronic illness prematurely out of one life stage into another, accelerating their "social clocks" and leaving them feeling "cheated" out of anticipated life stages (Bury, 1982). Middle age is often the last opportunity for achieving career and financial goals. The authors in this study were distressed to find that many of their future plans and goals would likely no longer be attainable. Singer (1974) equated chronic illness with premature social aging, the effects of which are considerably more distressing for younger patients. According to Erikson's (1968) model of psychosocial development, the stage of middle adulthood is a period of "generativity," the goal of which is to produce a contribution to society, whether by helping others or guiding future generations. Successful negotiation of the developmental tasks in this life stage prepares one for the final stage of late adulthood.

The blogs provided these authors an alternative route to completing the developmental tasks of the generativity period. They had created a unique compendium of medical and social knowledge which they used to help others. Several considered their blogs a legacy that would live on after their deaths. Many were also activists, raising money for research and treatment, advocating for patients, and working to raise awareness for their diseases. The blogs enabled the authors to create a "strategically revised identity" to replace their lost work identity and make a new place for themselves in the social world (Hunt, 2000).

A fourth problem area experienced by the authors was stigmatization and social rejection. Their multiple illnesses conferred on them a "spoiled identity" (Goffman, 1963) reflecting negative cultural attitudes toward aging and chronic illness (Millen & Walker, 2001). A few authors internalized their stigma and isolated themselves from society, but most found that a social quarantine had been imposed on them. According to Thorne (1993), those with stigmatizing illnesses experience social pressure to appear "normal"; failure to do so results in condemnation and social distance.

These authors were hurt by their social rejection and sought to understand its source. One explanation for the rejection of the chronically ill is that their stigma places a significant strain on social interaction, thereby disrupting interpersonal relationships (Crandall & Moriarty, 1995; Goffman, 1963). Albrecht, Walker, and Levy (1982) noted, "As the perceived costs of engaging in social interaction with a stigmatized person escalate, social distance increases" (p. 1325). People develop "abandonment rationales" enabling withdrawal from those whose illnesses are especially demanding or stigmatizing (Strauss & Glaser, 1975).

A second explanation for the rejection of the chronically ill involves the terror management perspective (Zebrowitz & Montepare, 2000). Individuals attempt to minimize their fears of dependency and death by projecting them onto members of some other group who "are perceived as sources of pollution and contamination to be avoided" (Crossley, 1998, p. 525). Older adults and those who are chronically ill are stigmatized because they represent mortality, bodily deterioration, and insignificance (Martens, Godenberg, & Greenberg, 2005).

The authors of these narratives were compelled to conceal their stigma by "passing," "covering," or otherwise keeping their illness and suffering to themselves. They experienced the double bind Thorne (1993) described: They needed to speak about their pain and limitations to account for their behavior but risked rejection by doing so. As Goffman (1963) explained, the stigmatized individual must act as if his or her burden is not heavy and that he or she is not different. By enacting a "phantom normalcy," the stigmatized individual might be granted a "phantom acceptance," but this conditional acceptance is withdrawn once the individual attempts to collect on "implied promises of consideration and aid" (p.

122–123). Stigmatization was also more of a burden for these authors compared with older adults. These authors were regularly confronted with the dissonance between their various productive and goal-oriented personal identities and their newly imposed (and unclaimed) social identities as "the disabled," and "the ill" (Dovidio, Major, & Crocker, 2000). Blogging increased the salience of their personal identities as "experts on their diseases," which elevated their social status (Miczo, 2003), and also provided a sense of connection to others.

A few authors acquiesced somewhat to the moral imperative to "think positively" perhaps as a means of seeking such acceptance. According to Miczo (2003), patients find they must present a positive attitude to be accepted by medical professionals, friends, and family members. Miczo noted that many who characterize their illness experience as transformative "find acceptance and closure at the same time they once again become acceptable to other members of society" (p. 480). Wilkinson and Kitzinger (2000) suggested that talk about positive thinking functions to enable the expression of negative emotions. By portraying oneself as a positive thinker, one is then allowed to speak about one's suffering with minimal sanction.

None of the authors in this article considered their illnesses a "blessing," or a "gift," but a few had attained what Kleinman (1988) referred to as "remoralization," recovering a sense of hopefulness that their illness had taken from them. Hopefulness in the context of chronic illness is not the expectation of a cure or specific outcome but rather a state of mind of courageous acceptance (Agich, 1995). Herth (1990) defined hope as an inner force that empowers one to transcend the present and progress "toward new awareness and enrichment of being" (p. 1256). Only one of the authors in this study appeared to achieve such a state of hopefulness.

Taken together, Strauss and Glaser's framework of chronic illness and Bury's concept of biographical disruption were useful for examining the experience of multiple chronic illnesses among middle-aged adults. Strauss and Glaser (1975) provided a foundation for understanding the labyrinthine quest for diagnosis, the complex process of illness management, the vital need for relevant information, and the ordeal of stigma and social rejection. Bury's (1982) concept of biographical disruption enabled us to appreciate the impact of the unexpected loss of the work identity and accelerated aging. These issues are indeed distressing when experienced out of "normal" chronological order, but they also have a considerable impact on identity and self-image. As the authors of these illness narratives illustrate, the experience of multiple chronic illnesses is significantly different for middle-aged adults compared with older adults.

Conclusion

The purpose of this article was to increase our understanding of the social effects multiple morbidity has for middle-aged men and women. We examined online illness narratives written by men and women between the ages of 36 and 59 who had been diagnosed with multiple chronic illnesses. The blogs ranged in duration from 14 months to 7 years allowing us to capture the authors' illness experience as it occurred in the present, but over an extended period of time.

The authors of these narratives experienced multiple morbidity as a continuous cascade of challenges falling into four categories: (a) diagnosis and management of multiple illnesses, (b) need for information, (c) identity dilemmas and threats to self-image, and (d) stigma and social rejection. We found that having multiple chronic illnesses differs from having a single illness in several ways: the symptoms of one illness make it more difficult to be diagnosed with another, one illness and/or its treatment often exacerbate another, and patients frequently receive fragmented care and contradictory advice (Fried et al., 2008; Schoenberg et al., 2011; Williams et al., 2007).

The experience of multiple morbidity also appears to differ according to age at onset. The middle-aged individuals in this article were able to aggressively seek out information, which enabled them to take responsibility for managing their illnesses, both of which would be more difficult for older individuals. For these authors, identity dilemmas, especially the relinquishment of their work identity, disrupted their anticipated life course trajectory and threatened to thrust them prematurely into a later life stage. Their experience of stigma and social rejection was more traumatic compared with older individuals more likely to accept illness as a normal part of the aging process (Hurd Clarke & Bennett, 2013). Through writing their blogs, these authors were able to derive meaning from their illness experience. They used their specialized knowledge to help others, and in so doing, were able to somewhat recover their place in the life course trajectory, and repair their self-image.

This study had several limitations. First, the sample size was small; however, given the frequency of posts, the average length of posts, and the longitudinal nature of the posts, we were able to analyze a substantial amount of data. Second, social data derived from the Internet come with a risk of decontextualization. To minimize this effect, we read the complete blogs, from their inception until the end of data collection, which provided the social context within which we interpreted the data. Third, as with anything appearing on the Internet, there is the question of authenticity. These narratives were unsolicited accounts written by individuals suffering from chronic

illnesses who expressed the desire to help others in a similar situation; we found nothing in the data to suggest they were not trustworthy. Finally, access to a computer and the Internet bespeaks a certain level of class privilege.

Given the rapidly increasing prevalence of multiple morbidity, especially among younger adults, it is necessary to better understand the experience of living with multiple chronic illnesses. This article's contribution is unique in that it sheds light on the experiences of an understudied yet important segment of the population, middle-aged adults with multiple chronic illnesses. The findings from this article can be utilized by health care providers, educators, family members, and other caregivers to better care for those with multiple chronic illnesses, especially those of younger ages. Areas for future research include specific combinations of chronic illnesses and the development of applications for practitioner use.

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