

University of St. Thomas, Minnesota

UST Research Online

Nursing Faculty/Staff Publications

School of Nursing

2003

Experiencing chronic illness: Cocreating new understandings

Pamela M. Ironside

Martha M. Scheckel

University of St. Thomas, Minnesota

Constance Wessels

Mary E. Bailey

Sharon Powers

See next page for additional authors

Follow this and additional works at: https://ir.stthomas.edu/mfcoh_son_pub

This Article is brought to you for free and open access by the School of Nursing at UST Research Online. It has been accepted for inclusion in Nursing Faculty/Staff Publications by an authorized administrator of UST Research Online. For more information, please contact asle4660@stthomas.edu.

Author

Pamela M. Ironside, Martha M. Scheckel, Constance Wessels, Mary E. Bailey, Sharon Powers, and Deana K. Seeley

Experiencing Chronic Illness: Cocreating New Understandings

Pamela M. Ironside
Martha Scheckel
Constance Wessels
Mary E. Bailey
Sharon Powers
Deana K. Seeley

This study was conducted as part of a research course in which new partnerships with area citizens and community-driven programs of research were developed. Working together, the teachers, students, and citizens were able to document their practical knowledge through conducting a study of the lived experiences of chronic illness using Heideggerian hermeneutical phenomenology. The pattern, Experiencing Chronic Illness: Cocreating New Understanding, and three themes emerged during the analysis of the data (a) focusing on functional status doesn't adequately account for the experience of chronic illness, (b) decentering the focus on the treatment of symptoms makes way for equally important discussions of meaning making in the context of chronic illness, and (c) the objectified language of healthcare covers over how chronic illness is experienced.

Keywords: *chronic illness; community-driven research; hermeneutical phenomenology; narrative pedagogy; hermeneutics*

This study was conducted as part of a seven-credit, two-semester graduate level research course that used narrative pedagogy (Diekelmann & Diekelmann, in press). The focus of the course was on creating new partnerships with area citizens and developing community-driven programs of research to initiate reform in nursing practice and education. New partnerships were created as citizens joined teachers and students in the classroom as learners, as participants in the study, and as members of the interpretive research team. Using Heideggerian (1959/1966) hermeneutical phenomenology, the teachers, students, and citizens were able to

AUTHORS' NOTE: We wish to acknowledge Dr. Nancy Diekelmann, Bonnie Ferguson, Teresa Davis, Julia Zimpel, and participants in the 2001 Nursing Institute for Heideggerian Hermeneutical Studies for sharing their insights, support, critique, and encouragement throughout this study. This study was funded by the Iowa College Foundation and presented in part at the 2001 Chicago Institute of Nursing Education, Chicago, IL.

QUALITATIVE HEALTH RESEARCH, Vol. 13 No. 2, February 2003 171-183
DOI: 10.1177/1049732302239597
© 2003 Sage Publications

document the practical knowledge of living with chronic illness, to create new understandings of how chronic illness is experienced, and to explore how these understandings can shape nursing practice and education. Described here is the pattern, *Experiencing Chronic Illness: Cocreating New Understanding*, and three themes that emerged during the analysis of the data: (a) focusing on functional status doesn't adequately account for the experience of chronic illness, (b) decentering the focus on the treatment of symptoms makes way for equally important discussions of meaning making in the context of chronic illness, and (c) the objectified language of health care covers over how chronic illness is experienced.

BACKGROUND

The incidence of chronic illness is increasing (Lindeman & McAthie, 1999). Krause, Stoddard, and Gilmartin (1996) estimated that in the United States, 19.4% of all noninstitutionalized citizens and nearly 64% of citizens between the ages of 75 and 84 have some degree of disability associated with chronic conditions. Factors such as advances in medical science and the successful treatment of diseases that were once terminal will surely contribute to an even greater prevalence of chronic illness in the future.

Despite its prevalence, there is little consensus among researchers regarding the definition of chronic illness. For the purposes of this study, a definition of chronic illness was synthesized based on input provided by citizen participants and a review of the extant literature. Chronic illness, in the context of this study, is a disease or injury that has lasted more than 6 months and has caused an individual to significantly alter his or her day-to-day activities. Alterations in daily activities may be due to factors such as decreased endurance, mobility, or cognitive functioning resulting in a limitation of the individual's ability to continue his or her usual lifestyle.

Few studies have been conducted investigating how individuals experience living with a chronic illness. When the client's experience has been studied, it has most frequently included analyzing only one illness or one dimension of a chronic illness. For example, some researchers describe individuals' experiences within a particular chronic condition, such as end-stage renal disease (Sloan, 2002), spina bifida (Monson, 1999), borderline personality disorder (Nehls, 1999), diabetes (Hunt, Valanzuela, & Pugh, 1997, 1998), or pain (Miller, Yanoshik, Crabtree, & Reymond, 1994). Other studies describe sociocultural influences of chronic illness such as neurasthenia and chronic fatigue syndrome (Ware & Kleinman, 1992), spinal cord injury (Fleishman et al., 2000), and mental illness (Lin, Inui, Kleinman, & Womack, 1982). Finally, some researchers describe factors associated with client coping (Hansen, Forcheimer, Tate, & Luera, 1998; Scioli, McClelland, Weaver, & Madden, 2000; Willoughby, Kee, Demi, & Parker, 2000) or quality of life (Duggan & Dijkers, 1999; Fletcher, Silva, & Sorrell, 2002) in the context of chronic illness. In these studies, the emphasis is on coping ability or quality of life rather than on how the participants experienced chronic illness in their day-to-day lives. Studying only particular chronic illnesses overlooks (albeit inadvertently) the common experiences and shared meanings that emerge across chronic illnesses, and isolating particular aspects of chronic illness for scrutiny, although helpful in some situations, inadvertently overlooks "the totality of the experience" (Thorne & Paterson, 1998,

p. 1). For example, the small acts, such as getting into and out of restrooms, that shape the day-to-day lives of many with chronic illness are covered over or lost when studies focus on only one disease or on a particular, isolated aspect of chronic illness. Compartmentalizing aspects of chronic illness denies both persons with chronic illness and clinicians new understandings of the meanings and significances of the holistic experience of living a life shaped by chronic illness. Because clinicians will care for an increasing population of clients living with chronic illnesses, it is timely to expand the body of health-related knowledge to include an understanding of how clients experience chronic illness.

The purpose of this study is to describe the common experiences and shared meanings of living with a chronic illness that are cocreated when teachers and students hear the stories of citizens who are experiencing chronic illness and, together with citizens, interpret their meanings using Heideggerian hermeneutics. By explicating commonalities with citizens, clinicians can extend their understanding of what is, and is not, helpful in caring for those living with chronic illness, thus illuminating new possibilities for care. Simultaneously, citizens cocreate with clinicians new understandings that reveal new possibilities for living day-to-day with chronic illness. Specifically the study findings revealed that (a) functional status does not adequately account for how chronic illness is experienced and needs to be augmented by narrative accounts, (b) discussions of meaning making in the context of living with chronic illness are as important for clients and clinicians as is the treatment of symptoms, and (c) the space between “acutely ill” and “being well” is poorly documented, yet this is where most persons with chronic illness dwell.

DESIGN

This study was conducted as part of a seven-credit, two-semester, graduate-level research course that focused on developing community-driven programs of research and creating new partnerships with area citizens toward reforming nursing education and practice. The course began with students talking informally to community members by asking them what nurses need to know to provide them with better care, collecting descriptions of contemporary nursing practice in the community from practicing nurses, and reviewing the nursing literature to determine what nurses are currently studying. Because narrative pedagogy focuses on sharing and interpreting lived experiences, following these activities, students were asked to identify a theme, similar to the process of identifying a theme in a short story, and to describe the meaning of that theme for nursing education and practice. When class members read aloud their interpretation of the themes they had identified, it became apparent how commonly issues surrounding chronic illness arose in the community and in the literature, and how narrowly clinicians understand how chronic illness is experienced by area citizens. The need for studies that document the practical knowledge of living with chronic illness through cocreating new understandings between clinicians and citizens was identified as an important area for research in this community. To that end, class members designed a study to investigate how chronic illness is experienced and used the remainder of the research course to gather the voices of teachers, students, and area citizens as partners in undertaking this study.

Following approval by the Institutional Review Board, class members identified area citizens known through personal or professional contacts to have a chronic illness. Citizens whose chronic illness had lasted more than 6 months and had caused a significant alternation in his or her day-to-day activities, whether due to decreased endurance, mobility, or cognitive functioning, were eligible to participate in the study. Participants determined whether they met the eligibility criteria. A sample of seven citizens with chronic illness was invited to participate in the study. This sample included individuals with spinal cord injury, chronic hepatitis, significant brain injury, multiple sclerosis, and Alzheimer's disease. Based on the physical and financial ability to travel to the college to attend team meetings throughout the semester and interest in sustained involvement in the study, three participants joined the class as members of the interpretive research team. No restrictions were imposed related to demographics, type of chronic illness, or degree of impairment. All participants were over 18 years and were able to understand written and spoken English. Informed consent was obtained from participants, and funding was provided by the Iowa College Foundation. At the request of participants whose stories are detailed here, the names used in this article have not been changed.

METHOD

The research team for this study included two experienced interpretive nurse researchers, five nursing graduate students, and three of the citizen-participants with chronic illness. Team members completed nonstructured, face-to-face interviews with each participant. Four of the interviews were conducted in participants' homes by individual students. Three interviews were completed during class meetings wherein the participant was interviewed by the teacher, students, and fellow participants. Interviews began with open-ended questions, such as "Can you tell a story about a time, one that stands out for you, because it reminds you of what it means to live with [the particular chronic illness]?" If further probing or clarification was needed, it was in the form of "What did that mean to you?" or "What was that like for you?" These questions were intended to keep the participants engaged in their stories without directing them to particular aspects or events (Benner, Tanner, & Chesla, 1996; Sorrell & Redmond, 1995). These interviews were audiotaped and transcribed verbatim for analysis. Data were analyzed using Heideggerian hermeneutical phenomenology to reveal the common experiences and shared meanings of living with chronic illness. The hermeneutic method for analyzing texts is briefly described below. The reader interested in examining the philosophical underpinnings of this method in more detail is referred to several excellent sources (Benner, 1994; Benner et al., 1996; Diekelmann, Allen, & Tanner, 1989; Diekelmann & Ironside, 1998; Draucker, 1999; Grondin, 1990; MacLeod, 1996).

Transcribed interview texts were distributed, and team members read each interview to gain an overall understanding of the text and to identify common themes. Bimonthly sessions were held, during which team members read aloud the themes they identified and their interpretation of these themes. According to Diekelmann and Ironside (1998), themes are recurrent categories that reflect the shared experiences and practices embedded within the interview texts. The citizens were encouraged to think of the interview texts as a story and to work with the class members to identify and explicate emerging themes. Each team member supported

his or her interpretations of identified themes with excerpts from the interview text. As subsequent texts were analyzed, team members discussed the common and differing interpretations that emerged. Vague or unclear meanings were clarified by referring back to the interview text. Because participants were members of the research team, questions that arose in the context of interpretation often elicited other stories or detailed aspects of a story not previously shared, adding to the richness of the data set and comprehensiveness (Plager, 1994) of the interpretation.

As the analysis of interview texts continued, recurrent themes, or those that emerged across multiple texts, were explored in more depth. With the analysis of subsequent interview texts, emerging themes were challenged and extended using critical, feminist, and postmodern literature; Heideggerian philosophical texts; and literature related to chronic illness. For example, feminist concerns with researcher-participant relations were brought to bear on the analysis when team members explored readings that considered issues such as how participants' voices are represented in research texts (Kirsch, 1999). Exploring a variety of texts during the analysis was not to seek or to justify one correct interpretation but to augment and illuminate the richness and complexity of the experience of chronic illness as it is lived (Diekelmann & Ironsides, 1998) and how that interpretation is to be communicated.

During the interpretive analysis of the study data, a pattern emerged. According to Diekelmann and Ironsides (1998), a pattern, the highest level of hermeneutic analysis, is constitutive, in that it expresses the relationship between the themes and is present in all study interviews. In this case, the pattern *Experiencing Chronic Illness: Cocreating New Understandings* describes how teachers, students, and citizen-participants came to grasp the common experiences and shared meanings of chronic illness explicated by the themes.

In addition, citizen-participants were consistently invited to cocreate as well as to confirm, extend, or challenge identified themes and the interpretive analysis. In this way, the rigor of the project was extended, and participants became partners in every aspect of the study. The rigor of the interpretations was further extended by having two citizens with chronic illness (one with fibromyalgia and the other with systemic lupus erythematosus) but not part of the study read the manuscript in its entirety for plausibility, thoroughness, comprehensiveness, and coherence (Plager, 1994).

The nature of Heideggerian hermeneutical phenomenology is reflective, reflexive, and circular, with interpretations being continually held open and problematic (Diekelmann & Ironsides, 1998). As such, the process of interpretation is never ending. Rigorous hermeneutic analysis elucidates new understandings and possibilities for living with chronic illness.

COCREATING NEW UNDERSTANDINGS: INTERPRETING NARRATIVES IN THE CLASSROOM

As we analyzed data, three themes were identified: (a) focusing on functional status does not adequately account for the experience of chronic illness, (b) decentering the focus on the treatment of symptoms makes way for equally important discussions of meaning making in the context of chronic illness, and (c) the objectified language of health care covers over how chronic illness is experienced. These themes

emerged as teachers, students, and citizen-participants reflected together on the transcribed narratives of chronic illness. That is, these themes were embedded in the participants' stories of chronic illness, and only when the research team members reflected together on the meaning of the stories did we come to understand the experience of chronic illness differently. Thus, by working together, each member cocreated new understandings of how chronic illness is experienced.

Participants in this study often began their narratives by describing their experiences of chronic illness in terms of the breakdown in or loss of their habitual body. Viewed phenomenologically, humans live in the world in a skilled and nonreflective way. The body becomes habitual, in that it is experienced as an extension of concerns and activities that are embedded with meanings and significances (Benner & Wrubel, 1989). Humans involved in activities do not experience such involvement as a series of steps or tasks to be completed. For example, when one walks down the hall to the drinking fountain, one experiences the activity of going to get a drink of water rather than the movements of the feet and legs, the swing of the arms, and the carriage of the torso for a defined distance on the way to getting a drink. However, in breakdown such as chronic illness, when the body is no longer able to function in the habitual way, activities are experienced differently and the nature of the lived or habitual body changes, requiring new understandings of living a life with a chronic illness. The experience of chronic illness can thus be understood only in the context of the lived-world because it is the lived-world that is made up of meanings and significances (Benner & Wrubel, 1989).

Many participants in this study described particular situations in which becoming disabled meant experiencing changes in taken-for-granted aspects living a life, changes that became problematic. The themes of focusing on functional status, decentering the focus on the treatment of symptoms and the objectified language of health care emerged in the context of the narratives gathered for this study. For example, Teresa, who sustained a brain injury leaving her with "the effect like I'd had a stroke on the left side of my body," described the meaning and significance of losing her habitual body and functional status in her day-to-day life:

It's really hard for me . . . my [two boys] are 5 and . . . 3 years old and if you have kids . . . you know they are very active. Every day with them, it's hard not to think about it *every day* because it's hard for me to stay home for an extended period of time by myself with my kids . . . I can't get down and play on the floor and wrestle around with them like anyone else can. I just can't. I can't get down on the floor by myself and get back up by myself to play with them and do the things they want to do. Now they're little enough like even my like my 5-year-old . . . doesn't remember me ever being any other way. So for him it is probably better because he doesn't know better but every day when I want to do stuff with them I remember. There used to be a time when I could have done that and it would have been OK. And taking them places. I can't. If I'm home by myself I can't go anywhere with the kids . . . because it's hard for me to get the 3-year-old in and out of the car by myself and I can't run after him if he starts to run out into the street by himself. I can't chase after him and make sure he is OK. He doesn't, you know he's 3 and they don't listen the best at 3. So basically if I have them by myself I have to stay at home with them, in the house. DAILY I am reminded how much life would be easier if I didn't have this.

Teresa describes how "every day" she is reminded of the things she cannot do: She cannot "get down and play on the floor," she can't get the kids into or out of the car, she can't run after them or keep them safe outside her home. Thus, she is

reminded “daily” of the limitations imposed by her chronic illness. Noticeably absent in Teresa’s story is the functional recovery from her illness or changes in her functional status. For instance, throughout her interview, she did not speak of the gains in the distance she could ambulate, or even the progression from a wheelchair to a cane, although these milestones were apparent in her stories. Rather, like other participants, the stories Teresa told were related to her ability to be involved in meaningful activities, such as taking care of her children. Viewed in this way, functional recovery, although clearly important, does not sufficiently account for the meanings and significances that make up her lived-world because functional recovery reflects only the physical and physiological aspects of chronic illness (Frank, 1995). A phenomenological account of chronic illness reveals the touchstones of meaning in the context of chronic illness—how chronic illness is lived.

Teresa’s story, like those shared by other study participants, revealed three common themes. First, it challenges the adequacy of focusing on functional recovery as the goal of health care. That is, focusing on functional recovery or status does not adequately account for how chronic illness is experienced. Although clinicians commonly articulate a patient’s ability (or inability) to attain and maintain certain functional milestones while recovering through constructing diagnoses such as “Alteration in mobility related to muscle weakness,” for persons with chronic illness who have lost their habitual body, meaning is not found merely in the decontextualized progression or deterioration of functional ability (Doolittle, 1994).

Second, the meaning and significance of functional status is the ability (or inability) to participate in activities that one sees as important. For Teresa, living with a chronic illness shows up not merely as symptoms to be treated, such as left-sided weakness or foot drop, but as the inability to “get down and play on the floor and wrestle around.” Thus, this theme reveals how focusing only on the symptoms Teresa experiences covers over the meanings of those symptoms in Teresa’s lived world.

Third, Teresa’s story makes clinicians mindful of how the objectified language of health care commonly used by clinicians to describe patients, such as “wheelchair bound” or “ambulates with cane,” although well intended, covers over and minimizes patients’ experiences. That is, the objectified language of functional recovery covers over the touchstones of meanings for participants, such as keeping one’s children safe. Perhaps objectified language strips important meanings and understandings from descriptions of the patients’ experiences—meanings and understandings that need to be restored.

These three themes recurred in Bonnie’s narrative. As Bonnie, a participant with multiple sclerosis (MS), told her story, she told of MS not as a diagnosis she lived with but as a way of living a life. Clearly, Bonnie’s experience includes juggling myriad medication regimes; searching for information about the disease, treatments, and related research; and finding resources to support her daily activities. Bonnie, however, also described a touchstone of meaning for living with MS as losing “control.”

You don’t want to get in the situation where you fall or that somebody has to pick you up. I’ve gotten better about that. Because like, relax, you know! [Things like that] happen and they’ve got to pick you up. But [falling] WAS a terribly embarrassing thing for me, or bladder control. I took yoga . . . better than a year ago and thought I could get the moves down a little bit. I had to adapt but I got into one

where at the end you were just relaxing and you were imagining yourself on the beach, the water was lapping, you know. Well . . . I REALLY went down somewhere, maybe I fell asleep, I don't know . . . but I finally heard [the instructor] say, "OK, wake up." Well all these people were awake and they were looking at me and . . . my bladder was just clinching and I had to go and I had to go now! I did not make it, well I made it but not before being incontinent. Well, then it's like "oh my God, I hope everybody's gone from the room, I hope, I hope, I hope" and I just scurried out and one person said, "So what, it's urine." But for me it was a MAJOR MAJOR loss of control, MAJOR. So . . . you [have to] learn that it ain't important.

Bonnie describes how, as lived, her chronic illness is a journey of trying not to "get in the situation where you fall [and] somebody has to pick you up." Embedded in Bonnie's realization that "things like that happen" is her knowledge that she must "learn" not count on her body in the usual taken-for-granted or habitual ways. Thus, the smooth and predictable functioning of her habitual body is replaced with many symptoms of breakdown (falling and losing bladder control, for example). Yet, the loss of her habitual body is more than symptomatic behavior or functional impairment in which she experiences the loss of the familiar ways in which her body responds in particular situations. That is, like Teresa, describing changes in Bonnie's functional status does not adequately account for her experience.

Also embedded in Bonnie's story is how symptoms are experienced. That is, although reassured by those around her, Bonnie's account reveals that it isn't the symptom itself (the fall or the incontinence) that is important. Rather, as lived, it is the meaning of the symptom that matters. Throughout her narrative, Bonnie describes adeptly dealing with symptoms, planning ahead to avoid risky situations and telling herself to "relax" and that "it ain't important." However, the meaning of the symptoms she experiences is an unremitting loss of the habitual body that she describes as a "MAJOR MAJOR loss of control." How do clinicians attend to the meaning symptoms have for clients? Although treating symptoms is important for persons with chronic illnesses, so is understanding the meaning of the symptom in the context of the lived-world. How do clinicians participate in meaning making with persons with chronic illness?

Another theme reflected in Bonnie's story is how the objectified language that clinicians use can cover over the ways in which chronic illness is experienced. For example, has clinicians' language inadvertently become coopted by the objectified language of health care in such a way that it covers over touchstones of meaning within chronic illness? How adequately does "Alteration in urinary elimination" describe and capture the experience Bonnie describes?

Julia, a participant with MS, also described the inadequacy of the objectified language of health care for describing how the symptoms she experienced as part of her chronic illness influenced how she saw herself. Having once been very active (hiking, mountain biking, figure skating, graduate school, and so forth) she now contends, "My life BEFORE the diagnosis was one thing and my life AFTER is another." As her symptoms progress, she finds that her body becomes devoid of its habitual way of being in the world. For Julia, becoming disabled requires a "whole new way of looking at myself."

What [I] used to be is not there anymore. I have to find a new way of describing myself. I can't say I'm healthy anymore. I have to find a new word. I have to find a whole new way of looking at myself.

Embedded in Julia's description of becoming disabled is the search for a language of possibility. Julia contends, "I can't say I'm healthy anymore," but she also resists describing herself as being ill. Despite the severity of her symptoms, she continues to participate in meaningful activities. For example, she maintains full-time employment, and she traveled nearly an hour one-way every other week for an entire semester to participate in this research study. Caught in the "between"—the expanse between being healthy and being acutely ill—Julia reveals how language fails to account for the experience of chronic illness. Rather, she searches for a "new way" or a "new word" to describe herself as she goes about creating new understandings of living a life with chronic illness. Perhaps, the objectified language of illness, disease, and disability that is commonly used in health care is inadequate to describe how chronic illness is experienced.

The objectified language of health care privileges the physical and physiological (functional) status of persons with chronic illness in such a way that the treatment of symptoms becomes salient. As such, when clinicians focus on treating symptoms, the meanings and possibilities within chronic illness are covered over. However, participants commonly described "coming to terms with" or "accepting" their chronic illness as living into a future of new possibilities. For instance, Bonnie described coming to terms with her chronic illness as "accepting the progression of MS."

Living with MS is ups and downs. I've had it for 14 years, so in the beginning when I was diagnosed . . . it was a death sentence, you know. [But] I did really well for probably 12 years . . . You become a control freak, I think. [I] plotted out my whole life. . . . I didn't have a wheelchair for a long time, and then I got a wheelchair that you can transport. But then it got to be where I couldn't take it out of the car by myself. So then my family had to take me to work [and] I'd always be late . . . But it made me learn to, by having to depend on other people, to let the control go. And that's not such a bad thing. You know it's just like the little crap doesn't matter and the big crap's pretty much going to take care of itself. It's not going to change much if I worry about it. It's not going to change much if I try to micromanage it. In a way MS has taught me that. . . . It's really humbled me. . . . It's taught me . . . to just kind of relax a little bit . . . I guess I'm more accepting of the progression of my MS. You know, it's kind of like, "Well, OK. We can do this, We'll just kind of work it a different way."

Initially hearing the diagnosis of MS as "a death sentence," Bonnie becomes a "control freak, [plotting] out her whole life." Yet, over the 14 years of her illness, she has learned to "let the control go," "to depend on people," and "to just kind of relax a little bit." As Bonnie describes letting the control go, she shares how she has learned that life is not an experience that can be controlled and "that's not such a bad thing." That is, living with chronic illness has afforded the recognition of the futility embedded in anyone controlling or attempting to control the human experience. Bonnie describes this realization as humbling, in that she has learned that "the little crap doesn't matter and the big crap's pretty much going to take care of itself."

Many participants, like Bonnie, described "letting go" as constitutive of their experiences of living with chronic illness. This letting go, however, was not a resignation or giving up but rather was a way of creating new understandings of living with chronic illness by knowing when and how to let go of control and controlling. Participants shared how living with a chronic illness has "taught" them a lot about being human and living-a-life and about which things "matter" and which do not.

Letting go, as described by these participants, is an understanding of the meaning and limits of control that releases one to be free for the possibility for "[living] in a different way." Heidegger (1959/1966) describes letting go as releasement toward things: "Releasement toward things and openness to the mystery belong together. They grant us the possibility of dwelling in the world in a totally different way" (p. 55).

Dwelling in the world in a totally different way is not merely learning to live with losing functional ability; it is also being attuned to possibilities. As participants described the meanings and significances of their chronic illness, they revealed the practical wisdom born from living with a chronic illness over time. For instance, Julia reveals the insights and practical wisdom she persistently learns in living with chronic illness:

You wanted to know what a day is like. [pause] Basically, the best way I can describe it is that, when YOU go to bed at night and you've worked real hard physically all day . . . you're very tired, extremely, every muscle is very, very tired. And you go to bed and you say, "Thank God I can lay down and just let it all fall." That's how I get up in the morning, that's how I START my day and I go down from there. And you have to, there's something that's taken me years to learn and I still haven't learned it, but I learn it some days, if you go beyond a certain point the only way to describe it is that you've hit a brick wall and that's it! You're done, you CAN'T EVEN WALK.

Julia's analogy of "[hitting] a brick wall" was used by many participants to describe overdoing it, pushing themselves too hard, beyond what their bodies could handle. When Julia states, "there's something that's taken me years to learn and I still haven't learned it, but I learn it some days," she reveals that what her body can handle changes, so that, "some days," she has learned to avoid hitting the brick wall. Implicit in this "some days" description is the knowledge that there will also be days when she has "[gone] beyond a certain point . . . and [she] can't even walk." Thus, for Julia, living with chronic illness revolves around reconstituting her bodily knowledge—persistently learning what her body can and cannot do. Learning what her body can (and cannot) do, however, is implicitly directed toward meaningful activities, such as being able to walk. Without being able to walk, Julia states, "you're done." Thus, the practical wisdom of learning her bodily limits or creating new understandings of living with chronic illness is not quiescent but directed toward keeping open a future of possibilities. How do clinicians account for the possibilities of living with chronic illness?

IMPLICATIONS

Forging new partnerships by working collaboratively with area citizens within the classroom provided the opportunity for teachers, students, and citizens to cocreate new understandings of living with chronic illness. As we collectively analyzed and reflected on the data in this study, the practical knowledge of living with chronic illness described by participants was documented. One of the themes emerging from this study reveals that living with chronic illness can never be understood as merely changes in functional status but must be understood in the context of each person's concerns and commitments. But how do clinicians ascertain the touchstones of meaning for clients within chronic illness? As clinicians document functional sta-

tus, is there concomitant documentation pertaining to how the client experiences this functional status? Have clinicians inadvertently set functional recovery as an optimal status (Doolittle, 1994)? The stories shared by participants in this study reveal how living with chronic illness goes far beyond living with the mere loss of functional ability. Rather, the meaning of living with chronic illness was understood by participants in terms of the possibilities of dwelling in the world in a totally different way.

Similarly, the practical implications of providing care to persons with chronic illness, revealed by the theme decentering the focus on the treatment of symptoms, illuminates the possibility for clinicians to move beyond the treatment and management of symptoms, to participate in meaning making with persons who have chronic illnesses. For instance, Julia describes how a nursing colleague provided meaningful care in her husband's absence:

If my husband's gone for a time, there's one nurse colleague . . . [who] comes down and gives me the injections that I can't reach. And the way she is the most helpful to me is that it's just like, "Let's have a cup of coffee." She treats it like it's NOTHING. Like I'm not a specimen, like I'm not this sick person. Like we're just doing an interaction between friends and I never FEEL like I'm a patient or an ill person, or handicapped, or . . . And that's very nice.

Embedded in Julia's description is how meaningful aspects of this nurse's practice are not the colleague's injection technique or the timeliness of administration, although these are clearly important. Rather, what stands out in Julia's account is the cup of coffee—the "friendly" interaction with the nurse colleague that signaled to Julia she was "not a specimen . . . not this sick person." Perhaps the importance of "friendly" interactions between clinicians and clients is overshadowed when teachers focus on treating and managing symptomatic responses. Do students learn to participate in meaning making with clients as an equally important aspect of health care as treating the symptoms that clients exhibit? Would exploring the meanings embedded in the symptoms that clients experience while living with chronic illness reveal hidden strengths, abilities, and possibilities?

Similarly, another theme emerging in this study reveals how the objectified language of health care covers over how chronic illness is experienced. Julia describes how "nice" and "helpful" it is to not be treated like a "specimen," and she searches for a new word to describe her self, which is neither "healthy" nor "acutely ill." How do clinicians speak of the chronically ill? Does our language focus on deficits and disabilities requiring intervention while the possibilities of living with chronic illness recede? Similarly, when citizens are brought into our classrooms, are they invited as "specimens" or cases of a particular disease, or as the teachers of practical wisdom?

As new partnerships were forged among teachers, students, and citizens in the context of this study, new understandings of living with chronic illness were cocreated and the practical wisdom of living with chronic illness was documented. Teachers and students gained new understandings of the inadequacy of focusing on functional status and treating symptoms in providing care to persons with chronic illness. The citizen-participants became teachers of practical wisdom rather than research subjects, specimens, or exemplars of a particular chronic illness. Similarly, citizen-participants gained new understandings of the possibilities of living-

a-life with chronic illness by pooling their knowledge, perspectives, and experiences with other participants alongside teachers and students. New pedagogies that authentically gather students, teachers, and citizens in classrooms (Diekelmann & Diekelmann, in press) and call for interpretive thinking about lived experiences reveal rich, multifaceted understandings of experiencing chronic illness. When teachers, students, and citizens join in community reflexive scholarship, new possibilities for practice and research emerge.

REFERENCES

- Benner, P. A. (1994). The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 99-127). Thousand Oaks, CA: Sage.
- Benner, P. A., Tanner, C. A., & Chesla, C. A. (1996). *Expertise in nursing practice: Caring, clinical judgment, and ethics*. New York: Springer.
- Benner, P., & Wrubel, J. (1989). *The primacy of caring: Stress and coping in health and illness*. Reading, MA: Addison-Wesley.
- Diekelmann, N., Allen, D., & Tanner, C. (1989). *The National League for Nursing criteria for appraisal of baccalaureate programs: A critical hermeneutic analysis*. New York: National League for Nursing Press.
- Diekelmann, N., & Diekelmann, J. (in press). *Schooling, learning, teaching: Toward a narrative pedagogy*. Madison: University of Wisconsin Press.
- Diekelmann, N., & Ironside, P. (1998). Hermeneutics. In Fitzpatrick, J. (Ed.), *Encyclopedia of nursing research* (pp. 243-245). New York: Springer.
- Doolittle, N. D. (1994). A clinical ethnography of stroke recovery. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 211-223). Thousand Oaks, CA: Sage.
- Draucker, C. B. (1999). The critique of Heideggerian hermeneutical nursing research. *Journal of Advanced Nursing*, 30, 360-373.
- Duggan, C. H., & Dijkers, M. (1999). Quality of life—Peaks and valleys: A qualitative analysis of the narratives of persons with spinal cord injuries. *Canadian Journal of Rehabilitation*, 12, 179-189.
- Fleishman, J. A., Sherbourne, C. D., Crystal, S., Collins, R. L., Marshall, G. N., Kelly, M., et al. (2000). Coping, conflictual social interactions, social support, and mood among HIV-infected persons. *American Journal of Community Psychology*, 28, 421-453.
- Fletcher, J. J., Silva, M. C., & Sorrell, J. M. (2002). Harming patients in the name of quality of life. In N. L. Diekelmann & P. M. Ironside (Eds.), *First, do no harm: Power, oppression, and violence in healthcare* (pp. 3-48). Madison: University of Wisconsin Press.
- Frank, A. W. (1995). *The wounded storyteller*. Chicago: University of Chicago Press.
- Grondin, J. (1990). Hermeneutics and relativism. In K. Wright (Ed.), *Festivals of interpretation—Essays on Hans-Georg Gadamer's work*. New York: State University of New York Press.
- Hansen, N. S., Forchheimer, M., Tate, D. G., & Luera, G. (1998). Relationships among community reintegration, coping strategies, and life satisfaction in a sample of persons with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation*, 4, 56-72.
- Heidegger, M. (1966). *Discourse on thinking* (J. M. Anderson & E. H. Freund, Trans.). New York: Harper and Row. (Original work published 1959)
- Hunt, L. M., Valenzuela, M. A., & Pugh, J. A. (1997). NIDDM patients' fears and hopes about insulin therapy: The basis of patient reluctance. *Diabetes Care*, 20, 292-297.
- Hunt, L. M., Valenzuela, M. A., & Pugh, J. A. (1998). Porque me tocó a mí? Mexican American diabetes patients' causal stories and their relationship to treatment behaviors. *Social Science & Medicine*, 15, 959-969.
- Kirsch, G. E. (1999). *Ethical dilemmas in feminist research: The politics of location, interpretation, and publication*. Albany: State University of New York Press.
- Krause, L. E., Stoddard, S., & Gilmartin, D. (1996). *Chartbook on disability in the United States: How many people have a disability and how do the levels of disabilities change with age?* Retrieved November 29, 2000, from <http://www.infouse.com/disabilitydata/p16.textgfx.html>
- Lin, K. M., Inui, T. S., Kleinman, A. M., & Womack, W. M. (1982). Sociocultural determinants of the help-seeking behavior of patients with mental illness. *Journal of Nervous & Mental Disease*, 170, 78-85.

- Lindeman, C. A., & McAthie, M. (1999). *Fundamentals of contemporary nursing practice*. Philadelphia: W. B. Saunders.
- MacLeod, M. L. (1996). *Practicing nursing: Becoming experienced*. New York: Churchill Livingstone.
- Miller, W. L., Yanoshik, M. K., Crabtree, B. F., & Reymond, W. K. (1994). Patients, family physicians, and pain: Visions from interview narratives. *Family Medicine*, 26, 179-184.
- Monson, R. (1999). Mothers' experiences of living worried when parenting children with spina bifida. *Journal of Pediatric Nursing*, 14, 157-163.
- Nehls, N. (1999). Borderline personality disorder: The voice of the patient. *Research in Nursing and Health*, 22, 285-293.
- Plager, K. A. (1994). Hermeneutic phenomenology: A methodology for family health and health promotion study in nursing. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 65-85). Thousand Oaks, CA: Sage.
- Scioli, A., McClelland, D. C., Weaver, S. L., & Madden, E. M. (2000). Coping strategies and integrative meaning as moderators of chronic illness. *International Journal of Aging & Human Development*, 51, 115-136.
- Sloan, R. S. (2002). Living a life-sustained-by-medical-technology: Dialysis is killing me. In N. L. Diekelmann & P. M. Ironsides (Eds.), *First, do no harm: Power, oppression, and violence in healthcare* (pp. 118-163). Madison: University of Wisconsin Press.
- Sorrell, J. M., & Redmond, G. M. (1995). Interviews in qualitative nursing research: Differing approaches for ethnographic and phenomenological studies. *Journal of Advanced Nursing*, 21, 1117-1122.
- Thorne, S., & Paterson, B. (1998). Shifting images of chronic illness. *Image: The Journal of Nursing Scholarship*, 30, 173-178.
- Ware, N. C., & Kleinman, A. (1992). Culture and somatic experience: The social course of illness in neurasthenia and chronic fatigue syndrome. *Psychosomatic Medicine*, 54, 546-560.
- Willoughby, D. F., Kee, C. C., Demi, A., & Parker, V. (2000). Coping with psychosocial adjustment of women with diabetes. *Diabetes Educator*, 26, 105-112.

Pamela M. Ironsides Ph.D., R.N., is an associate professor of nursing at Clarke College, Dubuque, Iowa.

Martha Scheckel M.S.N., R.N., is a doctoral student at the University of Wisconsin-Madison School of Nursing, Madison, Wisconsin.

Constance Wessels B.S.N., R.N., is a case manager at Mercy Medical Center, Dubuque, Iowa.

Mary E. Bailey B.S.N., R.N., is a nurse at the Genesis Medical Center, Davenport, Iowa.

Sharon Powers M.S.N., R.N., is a nurse educator at Finley Hospital, Dubuque, Iowa.

Deana K. Seeley B.S.N., R.N., is an admissions coordinator at CGH Medical Center, Sterling, Illinois.