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Indicators of Preclinical Disability: Women's Experiences of an Aging Body

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Abstract

This paper is derived from a larger multimethod longitudinal study of women's bodily experiences and coping practices before the onset of disability. Twelve women participated in repeated performance measures, in-depth interviews of daily life and physically challenging events, and observations of daily activities conducted over 18 months. Interpretive phenomenological analysis of textual data showed that women's bodies provided multiple indicators or symptoms of preclinical disability. These indicators informed the women that their body was out of synch with their environment; conspicuous during social activities; and vulnerable to becoming dependent on others, technology, or assistive devices to accomplish daily activities. Greater attention to bodily indicators or symptoms may offer a practical method for clinicians to identify preclinical disability.

Keywords

aging; women; preclinical disability; interpretive phenomenology; symptoms; body experiences

INTRODUCTION

There are 6.2 million more women than men in the over-65 age group (Gist & Hetzel, 2004). This is significant since women experience higher levels of functional disability and live longer with disabilities than men (Guralnik, Leveille, Hirsch, Ferrucci, & Fried, 1997). In 2003, 28 million (43%) women aged 65 and older in the United States reported experiencing some form of disability, with 11% having difficulty performing self-care activities, such as dressing and bathing (U.S. Census Bureau, 2003). This number is likely to swell, as the baby boomers constitute an increasing proportion of our population, presenting our nation with unprecedented challenges to our health-care system and health-insurance programs (Goulding, Rogers, & Smith, 2003; Manton, Gu, & Lamb, 2007).

Aging is associated with the increasing likelihood of disability each year of life (Centers of Disease Control and Prevention, 1999). However, there is wide variability in the disablement trajectory of older people (Fried, Bandeen-Roche, Kasper, & Guralnik, 1999). A significant percentage (19% to 32%) of functionally independent older adults become disabled within 2–4 years (Fried, Bandeen-Roche, Chaves, & Johnson, 2000; Guralnik, Ferrucci, Simonsick, Salive, & Wallace, 1995). Unfortunately, they often remain undiscovered by health-care providers until an event, such as a fall, precipitates the onset of disability (Andersen & Johnson, 1996). It is known that specific chronic conditions, such as diabetes, coronary heart disease, and arthritis, are linked with disability (Stuck et al., 1999). A diagnosis of chronic conditions

alone, however, has failed to discriminate older adults at risk for disability from those who remain able-bodied (Waite, Oddone, & Weinberger, 1994).

Similarly, functional performance measures accurately identify older adults who are at high risk for hospital usage and mortality (Reuben et al., 2002). Only a few measures, however, discriminate between high-functioning older adults from those who are functioning moderately well (Curb et al., 2006). Additionally, they may not reveal actual performance difficulties experienced in the home environment (Guralnik & Ferrucci, 2003).

Older adults are aware of physical deterioration before the development of overt functional limitations and reduce or modify task completion, which prevents a sense of difficulty (Fried, Herdman, Kuhn, Rubin, & Turano, 1991). Fried et al., (1991) called this transitional functional state “preclinical disability” (p. 299). As a result, researchers have measured preclinical disability within a domain of tasks to identify early warning signs that disablement is in progress (Fried et al., 1991; Wolinsky, Miller, Andresen, Malmstrom, & Miller, 2005; Wolinsky et al., 2007). Theoretically, identification of preclinical disability would afford the chance to intervene early when there is a greater chance to promote recovery and prevent the onset of disability.

Although clinicians commonly rely on patient’s symptoms, such as pain or dyspnea, as early warning signs of disease, no study has addressed the role of symptoms of preclinical disability. Identification of symptoms that indicate difficulty performing daily activities could lead to a practical method to detect older adults at high risk for disability. Therefore, this study was designed to explore the experience of preclinical disability in the daily lives of well-functioning older women.

METHOD

The philosophical approach for this study was interpretive phenomenology, which provides a method to describe complex, meaning-filled bodily experiences of human beings within their environment (Benner, 1994). This approach provided access to bodily sensations that informed older women of impending difficulty.

Participants

The setting for this study was a suburban community in a Midwestern state. Women were eligible if they were 60–80 years old, community living, middle class, and English speaking. They were excluded if they had significant physical or cognitive impairment. Eligibility was determined during a screening telephone interview and confirmed during an in-home performance assessment. For this study, being nondisabled was defined as able to obtain a summary performance score of ≥ 4 on the Short Physical Performance Battery (SPPB), which is composed of three performance measures: standing balance, walking, and chair stand (Guralnik et al., 1994; 1995). Cognitive status was determined using the Folstein Mini-Mental State Exam (Folstein, Folstein, & McHugh, 1975). Each woman had to score above 17 or 24 based on level of education (Crum, Anthony, Bassett, & Folstein, 1993).

The sample was comprised of 12 women (10 Caucasian, 1 African American, and 1 Asian American). At the time of recruitment, ages ranged from 62 to 80 years; 10 of the women were married and living with their spouse. The women had a variety of educational and occupational backgrounds. Although education ranged from 8 to 22 years, eight women had 12 or more years of education. All of the women were retired, but most had been employed in typical female occupations (teacher, nurse, and office staff). They had one or more chronic diseases, with a mean of 2.6 per person. Seven women had a Body Mass Index (BMI) of equal to or greater than 30 (mean BMI of 30, range 24–39). Every woman reported being physically active;

however, only eight of the women met the recommended levels of 30 minutes of physical activity on most days of the week (Blair, LaMonte, & Nichaman, 2004). None of the women currently smoked, but five were past smokers.

Human Subjects Issues

Institutional review board approval was obtained from the university that sponsored the research. The interviews were conducted in the women's homes, which provided an optimal setting because it granted access to information regarding spouse support and the physical structure of the home, such as presence or absence of stairs.

Participants signed and received a copy of the consent form at the beginning of the first visit. They were told that the purpose of the study was to understand their awareness of physical changes and ability to do everyday activities as they aged. All interview tapes, transcripts, and questionnaires were de-identified, and access to the transcripts was limited to our interpretive group to protect confidentiality. Names and addresses of participants were kept separate from data in a locked file cabinet. In this paper, all names have been replaced by pseudonyms.

Data Collection

The primary methods of data collection for this paper were the in-depth interviews, participant observations, and field notes. The researcher conducted interviews and observations on 6 to 12 occasions over 18 months. The spacing between data-collection sessions provided time for participants to reflect and notice bodily sensations and modifications of specific tasks that were ongoing or developing. It also provided time to review interview transcripts before the next scheduled visit.

The series of interview guides were developed to explore the lived experience of aging in the context of the women's life stories. All interview guides had been previously used (Doolittle, 1990; Phinney, 2000; Pohlman, 2003; SmithBattle, 2003; Weiss, 1996) or were recently piloted. The first two interviews consisted of questions regarding daily activities (Daily Life Interview) and personal perspectives on aging (Philosophical Perspectives on Aging Interview). A third, the Stress and Coping Interview, included questions regarding recent physically challenging events. The women described their bodily experiences and shared memories of their parents' aging experiences, their own personal health habits, fears about getting old, and thoughts about death. The interviews were semistructured to allow the women to talk about everyday activities. Probes prompted additional detail to clarify meanings and to provide a fuller description of the activities and events.

Interviews lasted between 60 and 120 minutes and were tape recorded and transcribed verbatim to provide a text for interpretive analysis. Emotions, such as laughing or crying, and notes about facial expressions and body movements were added during transcription to reflect the meaning in the words. Audiotapes were corrected by comparing the transcripts to the audiotapes to ensure accuracy.

The study included 4 or more hours of unstructured participant observations conducted in 1- to 4-hour periods occurring approximately every 2 months. Timing and location of the observations were based on data from the Daily Life Interview and the women's wishes. The researcher accompanied the women to places outside the home where they exercised, shopped, and volunteered. The women were encouraged to go about their activities as usual during the observations. Sights and sounds that occurred during the naturally occurring activity as well as how the researcher's presence might alter that experience were noted.

Field notes were recorded immediately after every visit following a protocol that detailed observations, impressions, and reflections of each data-collection session. For example, notes

included details about the woman's appearance and changes from previous visits along with thoughts, impressions, reactions, and emotions. It was helpful to make notes about specific questions that emerged so additional information could be collected during the next visit. Before each visit, the researcher reviewed field notes and previous transcripts.

A reflexive journal was maintained throughout the study to record the methodological decisions and additional thoughts and views regarding the data. This document provided a decision trail for rigor of the study by showing the decision process that led to the findings.

Data Analysis

Interpretive analysis includes three interrelated processes: thematic analysis, identification of paradigm cases, and exemplars (Benner, 1994). Analysis began with the first interview and proceeded concurrently with data collection. Initially, the transcripts were read to obtain an overall understanding of the story's meaning. Then texts were compared and contrasted to identify similarities and differences in practices and meanings (Allen, Benner, & Diekelmann, 1986). Throughout the interpretive process, selected transcripts were shared with an interpretive group, consisting of experienced phenomenologists, a philosopher, and doctoral students. Meeting with an interpretive group facilitated the process of interpretation, illuminated research bias, and identified statements that needed additional clarification during upcoming interviews. Lastly, the data generated and the researcher's interpretations were placed in context to form the findings. Koch (1996) referred to this as "co-constitution" of data. During the process of interpretation, the researcher's understanding was challenged, refined, and enhanced.

NVivo7, a qualitative software package, was used during thematic analysis to organize and facilitate access to text (QSR International, 2006). Early analysis of the interviews identified major themes and variations within the women's stories that described their preclinical symptoms. Key segments of text were gathered together under codes that were created during the initial readings. Initial codes for the symptoms of preclinical disability included *aches and pains, fatigue, stiffness, un-cooperation, and feeling off-balance*.

As the data were synthesized, themes that represented the bodily experiences of aging that corresponded to the symptoms of preclinical disability were identified. During this phase of analysis, each woman's bodily experience of aging was compared and contrasted with experiences of the other women.

FINDINGS

One overarching theme of *bodily indicators* was identified within the narratives where the women provided vivid descriptions of symptoms of an aging body. "Indicator" was chosen because the women did not refer to their preclinical symptoms as "symptoms." Although these bodily indicators were detectable symptoms of functional change or of an abnormal bodily condition, the women attributed these indicators to normal age-related changes and not to acute illness or to chronic disease. Therefore, they did not report them to their health-care providers until limitations created a major disruption in the women's ability to complete daily tasks.

The preclinical symptoms grouped into three types of indicators. The first type indicated that their body was *out of synch*, the second that their body was *conspicuous*, and the third that they were *vulnerable*. These indicators were central to the women's perceptions of well-being, the impact that aging was having on their lives, and the actions they took to adjust to their current functional state. The types of indicators are not mutually exclusive; rather, they reflect different aspects of the women's experiences. These are the basis of my findings about symptoms of

preclinical disability in older women and are described with the aid of verbatim excerpts from the women's interviews.

The Out-of-Synch Body

All of the women perceived a gap between themselves and their environment, on the biological as well as social level. The most distressing aspect occurred when they felt out of synch with others their age or older as described by Virginia (age 66):

When I look at my companions, the people I spend time with, my body seems older than theirs almost always. I have a friend who is 80, she dances up a storm and walks up a storm, and so my body makes me feel older.

On the social level, difficulty traveling and getting together with family and friends left them feeling the loss of lived synchrony with others. Like several other women, Alice (age 78) mourned the loss of family activities: "We used to go fishing together. I'd love to fish yet but I can't, you know."

Significantly, these women had experienced these symptoms for years:

I get tired more easily than I did 30 years ago, but I just think that's to be expected.
(Karen, age 67)

I don't have the energy that I had say 10 years ago. I can tell the years. (Shirley, age 75)

My knees don't hurt me but I don't have the strength, I guess. I would say it has been like that for 7, 8, or maybe even 10 years. (Alice, age 78)

The Out-of-Synch Body encompassed two related aspects: The Slow Body and The Demanding Body. The symptoms of The Slow Body included lower body changes such as a slower walking speed and difficulty getting up from low positions due to any reason such as pain or stiffness. The Demanding Body was stiff, sore, and fatigued. It demanded some type of action, such as rest or exercise, before activities could be resumed.

The slow body: "Give yourself plenty of time because it's going to take you longer"—The women were experiencing a state of being unable to keep up, a slowing of one's own time in relation to their own past bodily experiences and their perceived experience of others. They compared their body to other bodies, which they saw moving faster and easier through daily activities, and they felt slow, unable to keep pace, and therefore out of synch. As Virginia (age 66) stated, "Just don't plan too fast a pace. Give yourself plenty of time because it's going to take you longer going up and down stairs and getting in and out of the car." Their slow bodies limited their activities so they experienced difficulty completing daily tasks, such as housework. As Helen (age 80) explained: "I walk slower. I dust slower. I do everything slower than normal."

The demanding body: "I feel better once i move around"—The Out-of-Synch Body demanded time and attention during everyday life. All of the women explained that their bodies were predictably stiff and required movement (exercises or stretches) in order for them to regain some fluidity of movement. As described by Nancy (age 64), "Basically, every morning I do crunches and I do leg lifts because when I first wake up I'm fairly stiff so if I'm on the floor that helps me loosen up." Many of the women experienced repeated episodes of stiffness every time they sat "too long" as described by Helen (age 80): "If I sit too long I have a problem getting up, like if I go to the show or if I sit in the car too long." Two of the women expressed that the regular occurrence of stiffness created feelings of concern. This is evident in Nancy's (age 64) statement: "Sometimes I wonder if I'll ever reach a point that I won't be able to walk."

Additionally, their bodies often felt tired; therefore, time had to be devoted to some type of rest or relaxation every day. Once the women rested, their bodies allowed them to complete their daily activities. As described by Shirley (age 75): “Resting in the afternoon kind of relaxes your body because after all, at our age you can’t just go, go, go all day long without some form of relaxation and then you get up and you’re ready to go.”

The Conspicuous Body: “I Feel ... Kind of Like an Elephant Trying to Dance”—

Some of the women’s limitations, such as a wobbly gait, a swaying stance, or the painful inability to stand up straight made the women feel conspicuous. Karen (age 67), a youthful appearing woman, described why it was stressful for her to attend social functions:

I have a lot of problems staying in one place and not falling. I don’t know what it is, but I get really, really shaky. I call it the “willy-knees.”

The women described a sense of embarrassment when they were instinctively aware of being noticed by others and were afraid people perceived them as being impaired. Nancy (age 70) described an occasion when she was the last to arrive at a restaurant and “one my friends said ‘You are walking with a limp,’ and I wasn’t even aware of it.” Like Nancy, other women felt exposed at times when others noticed their difficulty.

The Vulnerable Body

The Vulnerable Body encompassed two related aspects: The Unreliable Body and The Threatened Body. The symptoms of The Unreliable Body included feeling awkward and off-balance and experiencing weakness in their arms and legs. The Threatened Body created the biggest fear experienced by all of the women: becoming dependent.

The unreliable body: “You want to be very careful”—Many of the women expressed feeling that their stiff and painful bodies were unreliable during everyday activities such as walking. As described by Alice (age 78), “You want to be careful how you step because if you step wrong you’re going to fall when otherwise maybe you wouldn’t. You can’t correct your foot quick enough.” They sensed a risk for pain and injury. In response, they took steps to protect their vulnerable bodies as described by Elizabeth (age 74): “I have to watch myself. So I kind of take my time and hang on if I can. I hang on to the banister when I go downstairs, if both hands are available, I’ll hang on with both hands.”

Although these were well-functioning women, bathing had already become a risky task because reduced strength and joint stiffness made getting out of the tub difficult. As Norma (age 70) stated, “I know I’m playing with danger using the tub, but the feeling that I get from sitting in the hot water outweighs the risk.” Shirley described how she exited the tub “carefully:”

Sometimes I have a little trouble getting in and out of the tub, but that’s why I like that garden tub because I cannot just rise up out of the tub, I have to roll over on my hands and knees and lift up that way. There are no bars; I’m just very careful.

A few of the women used assistive devices because they felt the risk of climbing in and out of the tub outweighed the benefits of soaking in hot water.

I do have to be careful getting in the tub. But no, otherwise I don’t have any trouble. Well, I shouldn’t say that. I have one of those handheld shower things because I don’t sit down in the bathtub because that’s too hard getting up because of stiffness and all of that. And if you slip and bump yourself, you really hurt. (Alice, age 78)

The threatened body: “The reality is that everyone is temporarily able-bodied”—

The biggest fear was that of becoming dependent upon others, technology, or assistive devices to accomplish activities. Norma (age 70) explained:

The future scares me, because I don't know what's going to happen to my body. Am I going to be able to stay in this house, do we need to clean the basement? No, it's scary.

DISCUSSION

These findings extend our knowledge of preclinical disability by describing women's symptoms that indicate disablement is in progress. The women in this study were experiencing a variety of symptoms that they attributed to aging. These symptoms indicated change or an abnormal condition of the body and were fundamentally important to the women's perceptions of well-being and the actions they took to adjust to their current functional state.

One overarching theme, bodily indicators, was used to describe the preclinical symptoms because the women did not consider them as symptoms. Three types of indicators that represented the bodily experience of aging were identified within the data: The Out-of-Synch Body, The Conspicuous Body, and The Vulnerable Body. These findings are similar to Bleeker and Mulderij (1992), who identified eight themes related to bodily experiences in disabled children: The Vital Body, The Rebellious Body, The Unreliable Body, The Sensitive Body, The Exercise Body, The Dependent Body, The Conspicuous Body, and The Incomprehensible Body. Plach, Stevens, and Moss (2004) discovered that women living with rheumatoid arthritis had three similar bodily experiences related to their "corporeality ... literally being in one's body" (p. 142).

The concept of corporeality was introduced by Merleau-Ponty (1962) to indicate that the body is the basis for all human experience. For it is through our body that we communicate and interact with people and objects. When the body is functioning normally, it tends to recede into the background and become absent (Leder, 1990). However, when we experience a change in health or physical functioning, the body becomes the central theme to our existence. The previously mentioned studies had one common feature: The participant's bodies had become a "thematic object of experience" (Leder, 1990, p. 14). This is best described by drawing on the work of Leder (1990, p. 4):

Insofar as the body tends to disappear when functioning unproblematically, it often seizes our attention most strongly at times of dysfunction; we then experience the body as the very absence of a desired or ordinary state, as a force that stands opposed to the self.

These findings also support the idea that older adults are aware of physical deterioration for months to years before seeking medical evaluation (Williamson & Fried, 1996; Mor et al., 1989). Reuben (1998) commented that a high proportion of older adults who are not currently functionally disabled are living in a state of "independence with difficulty" where they "sense an impending problem" (p. 139). These statements echo the findings of the present study.

Women are at high risk of developing disability. It is estimated that 32% of women aged 70 or older have difficulty or inability in performing daily activities (U.S. Census Bureau, 2003). Other recent findings showed that more women than men in the United States (40% vs. 37%) reported arthritis-related activity limitations (MMWR, 2006). Furthermore, this study supports the evidence suggesting that current measures of difficulty completing daily activities actually underestimates the prevalence of functional limitations in older adults (Gill, Hardy, & Williams, 2002). Only additional research will clarify these findings.

Limitations

The purpose of this study was to gain a deeper understanding of how well-functioning women experienced their bodies before the onset of disability. Only women were recruited. This might

be regarded as a limitation, as it might have been possible to articulate more clearly the particular experiences of women if they had been compared to those of men.

CONCLUSION

This study provides a deeper understanding of how women experience their bodies before the onset of disability. The women described a variety of subtle and often disturbing bodily sensations or symptoms that indicated disablement was in progress. However, they attributed these symptoms to a normal aging body. The preclinical symptoms grouped into three types of indicators, The Out-of-Synch Body, The Conspicuous Body, and The Vulnerable Body. The types of indicators were central to the women's perceptions of well-being.

Although these findings must be verified, they do raise interesting ideas for current clinical practice. For example, clinicians can help older adults learn to pay attention to bodily sensations and encourage them to report new or changing symptoms. Clinicians need to avoid disregarding these bodily sensations because the older adult appears healthy and well functioning. Underdetermination of the magnitude of difficulty experienced by older adults may limit the opportunity to support behavior changes, such as exercise, or to suggest assistive equipment that matches their particular needs. To reduce frailty, clinicians should use symptoms or indicators of preclinical disability as early warning signs of impending disability. Identification of preclinical disability would allow interventions to be provided earlier in the disablement process when they have greater opportunity to prevent disability.

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