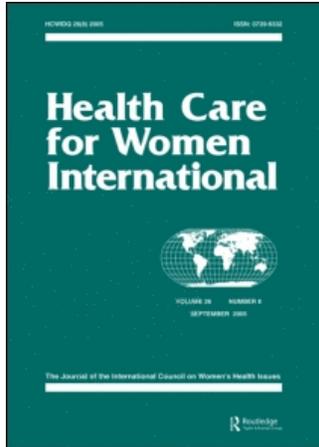


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Living With the Health and Social Inequities of a Disability: A Critical Feminist Study

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Living With the Health and Social Inequities of a Disability: A Critical Feminist Study

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Clients living at home with chronic disabling conditions together with their caregivers, service providers, and policymakers face major challenges in optimizing health care. In this critical feminist interpretive study we examined the experiences of women receiving home care for chronic disabling conditions. Five themes emerged: struggling with the embodied limitations of disabling chronic conditions; actively seeking health; struggling with service limitations; seeking ways to manage; and living with isolation and marginalization. Having done this study, we learned that home care services do not always contribute sufficiently to the overall health and well-being of women living with chronic disabling conditions and, in fact, may negatively impact upon their health.

The World Health Organization (WHO) has predicted that by 2020 chronic conditions will contribute to more than 80% of the global burden of disease (WHO, 2002). These chronic conditions include a multitude of bodily impairments and handicaps as well as diseases that restrict participation in daily activities and require management over years or decades. The WHO and the United Nations estimate that such disabling conditions account for about 10% of any national population (Coleridge, 1993; Health Canada, 1997; Rioux, 1998). In many countries as health care reform to address

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economic constraint has proceeded, the provision of care for individuals with chronic disabling conditions has broadened beyond hospitals to home and community.

In Canada an estimated 15% of the population has one or more functional, long-term disabilities (Statistics Canada, 1991, 1997). A large portion of disabilities are age related with chronic illnesses and their resulting restrictions in participation being more prevalent among those with low income, those who are older, and women in all age groups (Cassidy, Lord, & Mandell, 1998; Naegle, 1992; Statistics Canada, 1991). Little is known about the impact of health care restructuring on women receiving home care services for conditions of this nature (Armstrong et al., 2002; Aronson & McColl, 1999). As almost two-thirds of recipients of such care are women (Statistics Canada, 1991), investigation of the experience of home health care services for women with chronic disabling conditions seems particularly important.

To address this issue, we undertook research to critically explore this experience. We aimed to illuminate these women's perceptions and values related to life and health, their endeavors to manage their life and health, their experience with the community services intended to help them in managing their life and health, obstacles experienced in managing their life and health, and their perceptions of what services and resources should be developed to assist women living with chronic disabling conditions to manage their life and health.

LITERATURE REVIEW

The major recipients of home care, and therefore those most affected by the shift in health care delivery from hospital to home, are elderly women with chronic and disabling conditions. Despite advances in the women's health movement, little has been done to promote the health of this group (Armstrong, 2002; Sholzberg-Grey, 2000). Some report that health promotion has remained focused on young women and males; thus, strategies to promote health amongst women with chronic disabling conditions have been neglected. While disabled female care recipients have been found to experience insecurity and disempowerment as well as a lack of basic information, control or choice in home care services (Aronson, 2001; Aronson & Sinding, 2000; Buetow & Kerse, 2001; McWilliam, Ward-Griffin, Sweetland, Sutherland, & O'Halloran, 2002; McWilliam et al., 1999; Morris et al., 1999; Rimmer, 1999; Ward-Griffin & Ploeg, 1997), how women requiring care actually experience the management of their life, and health at home has not yet been explored.

HISTORICAL BACKGROUND

As early as 1500 B.C., the ancient Egyptians documented an interest in the well-being and care of disabled individuals (Winzer, 1997). The ancient Greeks and Romans cared for those injured in battle but practiced infanticide with children who were born deformed or sickly. In the Middle Ages, disability was associated with evil and witchcraft and the Church sanctioned abuse of disabled people (Barnes, 1994). In the Western world, as recently as the 1950s, disabled people were subject to legislation that was developed and enacted to “sterilize defectives” (Marks, 1999). Today, the WHO emphasizes the priority of health for all (WHO, 1986) and it is assumed that social enlightenment and advances in medicine, as well as social welfare, have ensured that disabled people are treated with humanity and respect which would enable them to have control over and improve their health. In reality, however, individuals living with chronic disabling conditions, in particular women, continue to face considerable social discrimination and stigmatization (Goffman, 1963; Cassidy et al., 1998; Marks, 1999).

Indeed, the socially constructed experience of stigma merits attention in considering women living with disabling conditions. According to Goffman (1963) it is not the functional limitations of impairment, but rather the negative and often punitive societal and social responses to it, that constitute the greatest challenge for individuals living with disabilities. Corbin and Strauss (1992) have described the experience of chronic illness as following a path or trajectory. Such trajectories have been illuminated through comprehensive research (Charmaz, 1999, 2002). Individual trajectories of chronic illness represent the cumulative effects of disabling conditions including physical symptoms, the impact of the illness on the individual’s social world, and their perceived self-identity. Individuals experiencing physical disabilities often are discredited by society and must struggle for full participation (MacDonald, 2003). Such stigmatization may be responsible for social inequities, such as inadequate funding of home care and inadequate income support. The consequences of being stigmatized in this manner may include self-derogation, suspiciousness, hostility, anxiety, defensiveness, and bewilderment (Goffman, 1963). Whether and how such stigma is a part of the experience of women with chronic disabling conditions in managing life and health care at home has as yet been unexplored.

METHODOLOGY AND METHODS

The theoretical framework of critical feminist theory was applied in conducting this study. The aim of critical inquiry is to critique and challenge ideologies of social injustice. The methodology is premised on the belief that the

relationship between the researcher and study participants should be based on a philosophy of equality and reciprocity, with active dialogue to achieve the research aims (Berman, Ford-Gilboe, & Campbell, 1998). Dialogue of this nature affords participants an opportunity to reflect upon, to explore, and to examine the social processes and contextual factors that influence their life. Consciousness raising occurs as a result of this critical reflection process, thereby exposing how the dominant interests of those who have power both shape and control the lives of those with less power. The knowledge created thereby empowers participants to understand how they may act to realize their own best interests and bring about broader social change (Burns & Grove, 1997). In feminist research, women's perspectives are afforded primacy (Hall & Stevens, 1991). The research was approved by a university's Ethics and Review Board.

Sample

Cognitively intact women living with chronic disabling conditions for which they were receiving in-home services were purposefully selected from a list of in-home clients provided by a key informant of a large home care program. The sample included women 65 years and over who had chronic cardiovascular, respiratory, or arthritic disease, and women 18–64 years diagnosed with functional disabilities such as quadriplegia, cerebral palsy, and multiple sclerosis. To achieve breadth of perspective, we created heterogeneity in the sample by selecting participants who differed in age, marital status, living arrangements, and category of chronic disabling condition. In keeping with qualitative methodology, sampling continued until theme saturation was apparent (Patton, 2002).

The 8 participants ultimately selected ranged in age from 25 to 90 years, although consistent with the demographic profile of clients receiving in-home care, 6 were over 65 years of age. Their life stories reflected a diversity of roles: self-employed artist, retired teacher/farmer/journalist, nurse, medical assistant, and homemaker. Three were widowed, 3 were divorced, 1 had never married, and 1 was married and lived with her husband. Four lived in rental apartments, 1 lived in a subsidized townhouse, 1 lived in a senior's housing complex, 1 lived in her own home, and 1 lived in her parent's home. Six of the women lived alone, 1 lived with her spouse, and 1 lived with her parents. Seven reported having an annual income of less than \$20,000, and 1 declined to state her income. Their disabilities were related to a variety of chronic disabling conditions including cerebral palsy, Frederick's ataxia, chronic obstructive pulmonary disease, chronic cardiac conditions, and arthritis. Several of the women had multiple health problems such as diabetes, coronary heart disease, and arthritis.

I am interested in understanding how you experience health and quality of life.

1. Please describe your everyday life.
 2. In your life what is most important to you?
 3. What are some of the challenges you face in a typical day?
 4. How would you describe your health?
 5. At this time what do you do to maintain your health?
 6. Please describe for me what it is like living with a disability.
 7. How does your community help you?
 8. What obstacles have you encountered in trying to maintain your health?
 9. What would you like to see happen in your community for women living with a disability?
 10. Is there anything else you would like to tell me?
-

FIGURE 1 Semistructured interview guide: Living With the Health and Social Inequities of a Disability: A Critical, Feminist Perspective.

Data Collection

After informed consent was obtained, a semistructured interview guide was used to conduct qualitative interviews in the women's homes. See Figure 1. This approach encouraged dialogue about the participants' everyday life and health, the challenges and obstacles faced in living with their chronic conditions, and ways in which their community had assisted or might assist them in optimizing their life and health experience. The interviews were audiotaped and transcribed verbatim. Field notes were kept regarding observations and reflections made during and immediately after the interviews.

Data Analysis

Hermeneutic interpretive analysis using immersion and crystallization techniques was conducted to identify themes and patterns emerging from the data (Patton, 1991). During this process, the researcher spent a prolonged amount of time immersed in the data, reading and rereading each transcript and reflecting on the content until an intuitive understanding or crystallization of the text was reached. Emergent themes were identified and used to interpret the lived experience of the participants in the sociopolitical context of their lives (Crabtree & Miller, 1999; Miller & Crabtree, 1992).

Authenticity

In critical research, trustworthiness is a primary element, involving the accurate and credible portrayal of the participants' voices (Guba & Lincoln, 1989). Techniques to promote credibility of the findings included tape-recording and verbatim transcriptions of the interviews to ensure accuracy of the data. Member checking was conducted with participants at the end of interviews, and after a preliminary interpretation was achieved, to ensure that participants' experiences had been captured accurately (Kincheloe & McLaren, 1994; Hall & Stevens, 1991). Peer review by thesis supervisors helped to ensure that

interpretation made sense of the data and enhanced in-depth understanding (Kuzel & Like, 1991). Consistent with critical research practice, through the member checking process, and subsequent sharing of emergent themes, participants were assisted in re-evaluating their current situation and in recognizing oppressive structures in their lives. Labeled “catalytic validity” (Lather, 1991), this activity has the potential to energize participants to take action in making changes to improve their lives.

FINDINGS

The findings of this study reflect the stories of a diversity of women with chronic disabling conditions. The in-depth exploration of the study participants’ experiences revealed the struggle with health and social inequities encountered by the participants, all of whom lived with chronic disabling conditions for which they were receiving in-home services. The following themes were identified from the emergent data: (1) struggling with embodied limitations; (2) actively seeking health; (3) struggling with service limitations; (4) seeking ways to manage, and (5) living with isolation and marginalization. The following sections illuminate each of these five components of their experience.

Struggling With the Embodied Limitations of Disabling Chronic Conditions

Each person must come to terms with and live with the limitations associated with their own body. Bodies are transformed not only by the natural processes of aging but also by illness, both of which may impact upon quality of life, which is a subjective response to one’s life circumstances (Ferrans, 1997). The women in this study struggled with the illness and needs related to their chronic disabling conditions, embodying their limitations.

Many of the participants in this study described living with a chronic disabling condition as a daily “struggle” of trying to make the best of their physical limitations. This struggle was captured in words such as “no bed of roses,” “frustrating,” and “restricted in so many ways.” One voiced the frustration of living an embodied experience of disability, limited energy and fatigue, and “never having a day go by that I’m not in pain.” Several described their inability to “depend” upon their bodies in managing activities of everyday life that normally are taken for granted. One described the following incident:

I was doing some work in the kitchen and I went to get up and my legs just folded up right under me two days in a row. . . . I went to get up and

I managed to make it with my walker to the chair there, and the second day I almost didn't make it.

Another observed:

I got a cloth this morning and was dusting . . . just dusting. . . . I was starting to get short of breath. . . . You see, when you can do things, you never even think about it, you never give it a thought. I used to keep this apartment just slicked up. . . . Now I can't. And, I'd love to take a bath. And I would like to be able to go [for a walk] down the street. I can't go to a mall or anything.

Actively Seeking Health

Despite their many physical limitations, the women in this study described how they made day-to-day attempts to restore, maintain, or achieve health: keeping a positive attitude; striving to maintain support; and making positive lifestyle choices to promote and sustain their own health.

Keeping a positive attitude was described by participants as crucial to living with the limitations imposed by their disabling condition. For them, keeping a positive attitude meant blocking negative thoughts and accepting their own limitations. As one stated, "I can't let it get me down." Another elaborated:

I just accept everything as it comes along, good or bad. If something comes along that I am able to do, I feel really good about it. But if I start to do something that tires me too much, I stop. Yes, I have really learned my limitations.

Another, who exercised "every day . . . to keep up my strength," described her belief that "your attitude and your determination . . . will make or break you." Another advised: "You've got to make the best of it. . . . I can't let it get me down. . . . I just don't think about it [my limitations]. . . . Keeping busy doing little things gets me out of feeling sorry for myself."

Many of the participants described striving to stay connected to family, friends, and God to maintain their health. In response to probing questions about how they maintained their health, several elaborated upon the significance of spiritual beliefs and actions in seeking health: "My faith is number one. I do amazingly well [in maintaining my health] because I have such a deep faith. . . . It gives me an inner strength to see and deal with things positively." Another affirmed: "Praying. Oh yes that helps a lot. . . . Without it I wouldn't know what to do [to stay healthy]."

Participants described the meaning that families bring to their lives and its relevance to being healthy. One emphasized, "Family is the most important

thing in the world to me. I've only got a sister, but she is the most important thing in my life." Several explained, "It gives me great pleasure to see them [grandchildren] growing up and going to school" and "I've got two great grandchildren and I never really thought I would see great grandchildren." Another observed, "The most important things are still with me [despite the chronic illness/disability trajectory]." Counted amongst these important things were friends and neighbors who provided instrumental support, including buying groceries, doing laundry, and accompanying participants to doctors' appointments.

Despite their struggle with embodied limitations the women described making a variety of positive lifestyle choices such as exercising and eating a healthy diet. As one woman explained:

I get lots of rest. . . . I usually go to bed around 10:00 and I sleep until I have to put those drops in my eyes. . . . I have a sensible diet. . . . I visit my doctor. . . . I take all my medications as prescribed . . . and that is about all I can do to maintain my health under the restrictions I am under. You see I can't exercise, which I would really enjoy. . . . I can hardly push that chair around without getting short of breath.

Overall, the women in this study appeared to actively apply ways to maintain and promote their health. Personal determination and initiative were apparent in their descriptions of enacting a variety of health-promoting behaviors.

Struggling With Service Limitations

All participants were receiving home care services that included visits from a homecare nurse or assistance from a personal support worker or both. The women regarded this service as essential to maintaining their independence, well-being, and even their life:

I couldn't get along without them. I couldn't. . . . I would be gone in no time, I know it. If my nurse wasn't here counting out my pills and if my homemaker wasn't here doing my washing and bathing me and doing my hair.

In this context of high need, study participants described their struggle with service limitations, including the system's failure to recognize their needs, to listen to their perspective, to provide services adapted to their individuality, and to provide adequate resources. As one explained, "I really need them done [floors washed], but there is nobody [to do this] because they are not allowed to do it."

Participants also observed that their service providers did not understand or were indifferent to their needs. When services were limited or ended,

however, many of the women in this study had to rely on assistance from family or friends or both to help them manage their life and health. Having to rely upon others contributed to feeling like a burden and often was accompanied by reluctance to “impose,” “beg,” or create “hassle” for family or friends. One explained, “Everyone seems to have commitments with family and work, so it is hard. Sometimes I feel like I put my family through so much.” Frequently the women would do without support rather than request assistance from family or friends, believing this to be an “imposition.” Despite these feelings, the participants did reluctantly accept and appreciate the support that family, friends, and neighbors provided, although as one said, “It [asking for help from friends and neighbors] destroys your self-esteem.”

Study participants further described their struggle with service limitations. Participants believed their voices in accessing required services often were not heard. For example, participants’ perceived needs did not always match needs as defined by the system:

It’s upsetting to hear [that the] CCAC [home care provider] doesn’t consider dusting and vacuuming for someone like me, because I see all of those things as part of one’s self-esteem. I feel that someone like me needs it more than ever.

The roles of personal support workers had been revised without input from the recipients of care and, in participants’ estimation, did not take into account their diverse needs. Additionally, the case managers who facilitated resources were viewed as “following the rules,” rules that participants were quick to observe they “didn’t make” as “their hands were tied.” Others felt that case managers would not be supportive in facilitating their access to resources, as “they are too busy cutting everybody off.” Another, who required support in all aspects of her daily living explained the inflexibility and time insensitivity of service provision:

If I’m tired, I can’t afford to sleep in, not even 15 minutes, because everything [services provided] is timed so closely. . . and then there would be a whole series of things, consequences, if I miss my care.

Several participants also described how their voice regarding when service was terminated was ignored: “I was getting along fine until they took it [personal support] away. As far as I was concerned, it was just out of the blue.” Another exclaimed, “It’s just the fact they’ve got you over a barrel, coming and going” and elaborated that although she wanted the service provider to “Just give me back enough time [service hours] so I can live,” she was afraid to ask for more hours in case she might have hours cut even further:

The doctor told me I should never try and get into the shower by myself. That's the only reason I am getting that [personal support], and I don't know how long that will last. She [service provider] said, "You don't really need help if you have all that equipment."

Participants also experienced limited resources, including inadequate services and assisted living accommodations. As one described, the "cutting back" of service "from three times a week to [service] once a week" engendered anxiety regarding her own ability to live independently in her own home:

I don't have . . . any family [to assist]. . . I was getting along just fine until they took it away [cleaning and laundry support]. . . I am completely on my own (crying). . . I don't know how I will manage.

There were more appropriate accommodations available for the elderly women with chronic disabling conditions than for the younger participants defined by the system as "disabled." Access to housing was not equitable for the elderly study participants either, however, as there was not enough housing available. One described her dilemma: "I'd like to move over there [retirement home], . . . but there is a waiting list." Limited resources not only directly disadvantaged these women, but also disadvantaged them indirectly, taxing their own limited financial and social resources as they tried to meet their own service needs.

Seeking Ways to Manage

The women in this study actively sought assistance to compensate for the service limitations. When services were limited or ended many of the women had to rely on assistance from family or friends or both to manage their life and health. Frequently, the women would do without support rather than request help from family or friends, believing the assistance to be an "imposition." Despite these feelings, the participants did reluctantly accept and appreciate the support that family, friends, and neighbors provide, although, as one said, "it [asking for help from friends and neighbors] destroys your self-esteem."

Having experienced cuts to homemaking and personal support services, many of the women purchased the assistance of various community services that could be accessed only by paying fees. Most of the participants reported a low income that was predominately dependent on the Old Age Pension. Several described how they "just barely" managed, often being forced to prioritize expenditures so that they could purchase the assistance they believed essential. One woman described her attempt to manage:

I can get my toenails cut, a girl comes in. . . . Really I don't like the way she does it but it is only \$10. XXX used to charge me \$45. I used to have a personal support worker to do the vacuuming, because I can't do that, but I can't pay her and she had to cut back on everything. I have got to pay to do my washing, \$10 per hour and sometimes \$20. . . . I've got to cut down on. . . . I don't know what, because my rent is going up.

Despite the fact that the women valued being their "own boss," most were willing to live in supportive housing that accommodated their needs. Participants recognized that, with their differently abled bodies, specialized housing rather than nursing homes "was safer" and better met their needs. Thus, women living in the community with chronic disabling conditions confronted their struggle with service limitations by seeking ways to manage their own life and health.

Living in Isolation and Marginalization

Almost all of the women described how their service arrangements had negative consequences for them. Having to rely upon others contributed to feeling like a burden and often was accompanied by reluctance to "impose," "beg," or create a "hassle" for family or friends. One woman explained, "Everyone seems to have commitments with family and work, so it is hard. Sometimes I feel like I put my family through so much." One consequence of reluctance to having to seek assistance they required from informal sources was isolation. As one noted, "I haven't been out of the house for about 3 months." Others complained of "getting out" only "on rare occasions," as "getting out" was contingent upon available transportation, access to buildings, and support persons to assist them.

All participants expressed a desire for opportunities to relate to peers. Even if they did receive the assistance they required to "get out," however, many of the participants noted a lack of community opportunities for leisure and recreation, as one woman said, "I have no activities to speak of, except to get up." Several women conveyed some concern about the inappropriateness of leisure and recreation activities that did exist. For example, several had experiences in nursing homes where they would share organized leisure or recreational activities with those who were cognitively impaired. As one explained, "Activities are pretty boring sometimes because there are some who, if we play games. . . . can't grasp them." Others experienced enforced isolation as they responded to the advice of well-intentioned care providers: "He [the doctor] said, 'Okay, so if I let you out with that walker, and you fall, who is going to pick you up or see that you get picked up by somebody?'"

Ultimately the participants' experiences of struggling with their physical and service limitations and consequent isolation led to living in

marginalization. Marginalization is defined as the peripheralization of individuals and groups from a dominant central majority (Hall, 1999). Marginalized individuals differ from the dominant norm and are oppressed in that they lack power, are not valued, and are excluded from the sociopolitical processes of the dominant society in which they live (Hall, 1999). Overall, the experience of living with their chronic disabling conditions contributed to becoming and being marginalized, which altered the participants' sense of worth. Their confidence in their own ability to manage was undermined, thereby intensifying their personal experience of marginalization.

The Holistic Experience of Living With the Health and Social Inequities of Chronic Disabling Conditions

In this study, *the holistic experience of living with the health and social inequities of chronic disabling conditions* was one of *actively seeking health, struggling with service limitations, and seeking ways to manage* and participate in many activities of daily living, activities often taken for granted by those without a disability. Ultimately, however, women living with chronic disabling conditions experienced *isolation and marginalization*. The holistic experience of living with a chronic illness/disability was situated within a context fraught with health and social inequities that meant being marginalized. The marginalization of study participants occurred despite their personal efforts to actively seek health and seek ways to manage in the context of service limitations.

DISCUSSION

While the insights gained from interpretive critical feminist research cannot be generalized, the findings of this study may be applicable to others in similar contexts (Kincheloe & McLaren, 1994). The insights gained add to a small but growing awareness of the social injustices contained within the experience of women living with disabilities (Armstrong et al., 2002; Aronson, 2001, 2002; Aronson & Sinding, 2000; Morris et al., 1999). The embodied limitations associated with aging and functional disabilities as experienced by the women who have them are situated within a context fraught with disadvantages. In a society that values youth, beauty, and able bodies, women with disabilities, through no fault of their own, are readily differentiated from the dominant cultural norm, a norm based on an idealization of the body that reflects neither the natural course of human development nor the limitations of physical impairments (Bickenbach, 1993; Fawcett, 2000; Wendell, 1996).

The findings of this study are consistent with the thinking of Marks (1999), who hypothesizes that individuals who are disabled are subject to negative stereotypes and are ultimately devalued (Armstrong et al., 2002). Often they are perceived as a net burden to society and are rejected because able-bodied individuals possess a deep fear of becoming disabled. The findings of this study also reflect the social discrimination and stigmatization others have observed (Goffman, 1963), in this instance created in part by the nature and structure of community-based services. As was discovered in previous qualitative research with seniors (Brown, McWilliam, & Mai, 1997), the participants in this study also described a lack of access to adequate in-home services and resources and to other community services including assisted living accommodations, transportation, and recreational and leisure activities. In total, study findings convey the isolation and marginalization in the everyday life and health of women living with chronic disabling conditions.

These findings invite attention to strategies that counteract the marginalization of women living with disabilities, not only to undo the social injustice contained within this reality, but also to strive toward the aim of optimizing society's collective human potential for the benefit of all. Historically, women have been relegated to the private world of their homes where care has always been considered to be a private responsibility (Fawcett, 2000). This traditional view continues to be reflected in and supported by the neo-liberal philosophy that dictates and justifies current trends toward limiting publicly funded services. Health care is increasingly strategically controlled by a global trade movement that manipulates governments to adopt this approach and necessitates that people buy their own services (Armstrong, 2002; Armstrong et al., 2002; Pollock, 1999). Within this sociohistorical context, women with disabilities are particularly disadvantaged. The findings of this study underscore the importance of specifically attending to the impact of policy promoting private purchase of services on women with disabilities and the need for publicly funded services for this disadvantaged group in both policy making and health service delivery.

In Canada, as in several other nations, legislation ensures access and equity for all medical services in hospitals, but there is a lack of legislation to address the changing picture of where and how health care is provided in the community context. Currently, there are no national standards for community-based care to ensure equity and access to and adequacy of needed health care services by individuals receiving in-home care. As health care in Canada has shifted from hospitals to in-home care, many services and resources once accessed through hospitalization, including personal care, meals, equipment, and medications, have been lost to those requiring care, and the costs for these services have had to be absorbed by the individuals themselves. As the experiences of the participants in this study indicate, even

in nations with publicly funded health care, women with chronic disabling conditions currently confront increasing pressure to assume responsibility for meeting their own care needs. Furthermore, the extra pressure to conform to system expectations for self care and support also was apparent, and participants described nonresponsiveness to their needs and concerns.

To meet their care needs, the women in this study, the majority of whom were in the low-income bracket, described their experience of paying for services that they could not afford. This finding supports other research identifying that income supplements such as old age and disability pensions are inadequate, particularly when individuals are expected to absorb the costs of care (Morris et al., 1999) and invites consideration in setting health care policy regarding service coverage in a publicly supported system.

When services and resources were unavailable, the participants in this study became dependent on family, friends, and neighbors for needed support. This finding is consistent with currently reported growth in voluntary service, which, along with private sector service, has been documented to be replacing public services (Aronson, 2002). The participants in this study often experienced the reliance on informal caregivers as being a burden. As well as lowering participants' self-worth, this sometimes resulted in the women going without the needed support because they were reluctant to "impose" or because they worried about the burden of care placed upon their families. Furthering this problem, voluntary services (for example, for transportation) were sometimes inadequate, as the demand exceeded the supply. Indeed, caregiver burden and the cost of volunteerism to society at large are major issues (Sholzberg-Grey, 2000; Sisk, 2000). These findings suggest the importance of more in-depth attention to the social and moral imperatives linked to informal and formal care, in particular, the social and psychosocial consequences of off-loading onto families and informal caregivers care responsibilities associated with disablement.

CONCLUSIONS AND RECOMMENDATIONS

While the findings of this study portray the experiences of women living with chronic disabling conditions in a nation with a publicly funded care system study, the struggle encountered has perhaps even greater relevance in nations where no publicly funded health care and social support exist. The findings evoke several recommendations to promote greater health, well-being, and social justice for women living with disabilities. Initially, cuts in publicly funded services may appear to benefit taxpayers. In reality, however, without a comprehensive system of publicly funded health care services, particularly for home care, the public shoulders the costs of their own health care. People requiring continuous long-term cares are especially disadvantaged. Women

with chronic disabling conditions, most of whom are in the lowest income bracket, particularly need this publicly funded support.

As this trend continues, it is critical that society, in general, concerned citizens, advocacy groups, policymakers, and academic audiences be informed about the impact of health service reductions so that they might take well-informed action. Health professionals in leadership positions must adopt an ideological position and commitment to identify social structures and policies that negatively affect health. They must facilitate the obtaining of data that support claims of reprehensible health care practices and critique the structures that sustain and support such conditions, recognizing how the interest of others (who are more powerful) dominate and control social structures that shape the lives of those less powerful, in particular women living with chronic disabling conditions.

First, health and social service leaders in practice, education, and research must foster dialectical discussions with women living with chronic disabling conditions on how to gain the necessary power to change and control their lives (Campbell & Bunting, 1991; Henderson, 1995; Thompson, 1987). Second, the resources that individuals living with chronic disabling conditions require often are needed to address broader determinants of health beyond medical needs. As participants in this study have illuminated, there is an urgent need for appropriate publicly funded assisted living accommodations, transportation, personal support, and leisure and recreational activities for individuals living with chronic disabling conditions, and a need to listen to the voices of these women regarding the resources required.

Health professionals practicing in home care settings must recognize the needs of these recipients of care, advocate on their behalf, and promote health in accordance with its broader determinants. The findings of this study suggest that health professionals may need to acquire more knowledge of the broader determinants of health, not only to promote health, but also to avoid inadvertently adopting a "blame the victim stance." As findings from this study indicate, this practice refinement particularly may benefit women living with chronic disabling conditions.

Third, the assumption that individuals must be responsible for their own well-being or that their families must provide their supports reflects a neoliberal value based on individualism. This thinking must be challenged. New models of publicly funded care are required. As the findings of this study suggest, providers endeavoring to achieve efficient service delivery on behalf of the system undermine the voice of women who have the knowledge, the desire, and the ability to participate as full partners in managing the care they require to optimize their life and health despite their disabilities. All health and social service providers require education about the experience of women living with chronic disabling conditions so that they are more critically conscious of their approach to care of these individuals and can develop and implement strategies that engage these individuals in decision

making about their care and promote fuller integration into their communities (McWilliam et al., 2002).

As health care in the twenty-first century is becoming increasingly community based, students in health and social service professions will require more opportunities to learn “about,” “in,” and “with” the community to ensure their understanding of the unique challenges confronted in this context. Curricula must address these learning needs and also must incorporate theoretical knowledge of aging and disability, thus promoting understanding of the needs of elderly and disabled women, who constitute the growing majority of care recipients.

Finally, the findings of this study invite more in-depth research investigating the lives and health of women with chronic disabling conditions. Specifically, researchers might further examine the impact of the shift from institutional to community-based care on women who are the major recipients and providers of care. Researchers also might examine what models of care are most effective in promoting health and well-being in women living with chronic disabling conditions.

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