

Aging with Long-term Physical Impairments: The Significance of Social Support*

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RÉSUMÉ

Cet article examine les situations de la vie et l'accès à la prise en charge sociale des personnes vivant dans des communautés, qui sont âgés de 50 à 65 ans, et qui ont vécu avec une déficience physique significative depuis plus de 15 ans. Les données ont été recueillies par le biais d'entretiens approfondis et semi-structurés avec huit hommes et femmes. Les conclusions suggèrent que faire face à la dégradation à long terme peut être une expérience solitaire lorsqu'un individu ne dispose pas d'un réseau solide de la famille et/ou des amis à apporter le soutien émotionnel. Selon les participants, leurs expériences du vieillissement avec déficience à long terme ont été améliorées lorsqu'ils partagent les pensées, les sentiments et les problèmes avec d'autres. Les conclusions montrent également l'importance du genre concernant l'accès à l'assistance sociale, et indiquent l'importance d'utiliser des ententes subjectives pour déterminer le niveau de soutien social disponible aux individus. Plus généralement, les conclusions soulignent que les personnes qui vieillissent avec des déficiences plongent dans, et souhaitent entretenir, des relations réciproques.

ABSTRACT

This article examines the living situations and access to social support for community-dwelling people between the ages of 50 and 65, and who have lived with significant physical impairment for more than 15 years. Data were gathered through in-depth, semi-structured interviews with eight men and women. Findings suggest that coping with long-term impairment may be a lonely experience when the individual lacks a strong network of family and/or friends to offer emotional support. Participants felt their experiences of aging with significant long-term impairment were improved when they shared thoughts, feelings, and problems with others. Findings also show the significance of gender regarding access to social support and point towards the importance of using subjective understanding when ascertaining the level of social support available to individuals. More generally, findings underscore the broader point that individuals aging with impairments are immersed in and wish to maintain reciprocal relationships.

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Significant numbers of people are growing older with pre-existing impairment, and this population continues to increase. In Canada, according to the 2006 Participation and Activity Limitation Survey (PALS) which is a post-censal survey of people who self-

identify on the census questionnaire as having activity restrictions, 15.1 per cent of those aged 45 to 54 and 22.8 per cent of those aged 55 to 64 reported a disability (Statistics Canada, 2006). These rates represent an increase from 2001 rates. The overall rates for reporting a

disability in 2001 was 12.4 per cent compared to 14.3 per cent in 2006. Indeed, for every age range, the 2006 disability rate was higher than it was in 2001 (Statistics Canada, 2007). Accordingly, it becomes increasingly important to understand the experiences of those aging with disability so that their needs may be taken into account in planning for social services. To foster a further understanding of their needs, in this article we report on the findings of a small-scale study of the experiences of community-dwelling people who might variously be called middle-aged or the young-old, and who have lived with significant physical impairment for more than 15 years. The focus is on their living situations and access to social support.

Physical Impairment and the Significance of Social Support

Social support can be conceptualized as encompassing three different domains: informational, instrumental, and emotional (House, Umberson, & Landis, 1988). These three areas are highly correlated (Thoits, 1995) and important for people aging with long-term physical impairments. For example, by having others to rely on for social support – whether physical, informational, and/or emotional – people typically find it easier to cope with the aging process, and they are helped to improve their quality of life (Holicky & Charlifue, 1999).

Having access to information about what to expect is important for people dealing with health issues. As Helgeson and Cohen (1996) found in their study of cancer patients, learning how to manage symptoms reduced confusion in patients and helped them cope better. Yet information is often lacking for people aging with long-term physical impairments, which can make it difficult for them to cope with unanticipated changes. For example, the participants in research by DeSanto-Madeya (2006) described aging with a spinal cord injury as “stumbling along an unlit path” (p. 275).

To better delineate the concept of social support, Finfgeld-Connett (2005) performed a meta-synthesis of findings from qualitative studies of social support in relation to acute and chronic conditions, and to linguistic analyses of the concept. She found that social support is a dynamic, interpersonal process that involves the reciprocal exchange of information (p. 6). She argued for conceptualizing social support as either emotional or instrumental, and found that the provision of instrumental support included (a) the provision of tangible goods such as food, money, or shelter; and (b) the provision of services such as transportation, physical care, and assistance with household tasks. Emotional support, on the other hand, could be seen as comprising comforting gestures designed to prevent or alleviate emotional distress, and it did not necessarily depend on

physical presence. Finfgeld-Connett also found that social support networks consisted primarily of family and friends rather than professionals, and recommended that professionals find ways of encouraging their patients to use and enhance this lay resource (p. 8).

A considerable body of research makes it clear that having easy access to social support – whether informational, instrumental, and/or emotional – helps considerably as people with impairments cope with daily life (e.g., DiLorenzo, Becker-Feigeles, Halper, & Picone, 2008; Holicky & Charlifue, 1999; McColl & Skinner, 1995; Thornton & Lea, 1992). For example, stroke survivors in focus group discussions spontaneously identified social support as a key factor influencing their quality of life and indicated the importance of being able to maintain essential social relationships (Lynch, Butt, Heinemann, Victorson, Nowinski, Perez et al., 2008). This finding is congruent with other research showing the crucial importance of social support for determining post-stroke quality of life (Carod-Artal & Egido, 2009). Similarly, when adults who live with a variety of impairments and conditions such as cerebral palsy, multiple sclerosis (MS), amputation, and spinal cord injury (SCI) were asked to discuss health and wellness, they spoke broadly about the positive benefits of social support (Putnam, Geenen, Powers, Saxton, Finney, & Dautel, 2003).

Regarding the issue of aging with impairment, Ballantyne, Hawker, and Radoeva (2001) found that married individuals with severe arthritis said that the support they received from their spouses allowed them to cope with their illness. Indeed, many said that the availability of this support was essential for allowing them to remain in their own homes. DiLorenzo et al. (2008) interviewed married individuals over the age of 60 about their experience of adapting to MS over time, and all participants stressed the importance of receiving social support from spouses, family, and friends. Interestingly, they also said that as they aged they became increasingly willing to utilize social support, which suggests that age is a significant variable mediating experience. Subsequently, DiLorenzo, Halper, and Picone (2009) examined the relationship between age and quality of life in three groups of adults with MS and found that those aged 50 to 64 reported the poorest quality of life, regardless of physical functioning or duration of MS. Apparently, there may be something about being in the age group 50 to 64 that can make it especially difficult to cope with having physical impairments.

Research also highlights the importance of recognizing that people aging with impairment are involved in reciprocal social relationships that they wish to maintain. For example, in one study, many of the women aging with SCI worried about damaging their relationship

because they relied heavily on their partner for extra support (Pentland, Walker, Minnes, Tremblay, Brouwer, & Gould, 2002). Other research shows that people aging with impairments worry about being a burden to their family (e.g., Charmaz, 1994; Pentland, Tremblay, Spring, & Rosenthal, 1999; Putnam et al., 2003; Stone, 2007a).

Gender makes a difference regarding whom people turn to for emotional support. Women are likely to rely on non-familial support networks to discuss feelings about illness (Allen, Goldscheider, & Ciambone, 1999; Zakowski, Harris, Krueger, Laubmeier, Garrett, Flanigan et al., 2003) or for emotional support in general (Pentland et al., 1999, 2002). On the other hand, men with chronic illness are likely to turn to a spouse or other family member rather than friends for emotional support (Ballantyne et al., 2001; Charmaz, 1994; Gibbs, 2005; Harrison, Maguire, & Pitceathly, 1995; Solimeo, 2008).

At the same time, it would be problematic to assume that married people necessarily have access to social support from their spouse – not all marriages are experienced as supportive (Allen et al., 1999; Ballantyne et al., 2001; Birditt & Antonucci, 2008). Allen, Ciambone, and Welch (2000) have suggested “a cautionary attitude toward conventional wisdom that married people have adequate social support in times of need” (p. 336), and argue that this may be particularly true for middle-aged people who are ill or disabled. It is likely that middle-aged people with impairments are not having their support needs met, particularly when they live in the community and rely on informal care.

Indeed, research suggests that when individuals are seeking empathy, sympathy, or understanding, family members are not necessarily the best people to turn to, if only because they do not have direct experience of what it is like to live with chronic impairment (Cohen, Underwood, & Gottlieb, 2000; Fong, Finlayson, & Peacock, 2006; Helgeson & Cohen, 1996; King, Willoughby, Specht, & Brown, 2006; Pentland et al., 2002; Schwartz & Sendor, 1999; Stone, Hill, Kawchuk, Lefrancois, Maki, Mantis et al., 2002). This literature shows that, regardless of whether someone has familial support, support groups can lead to an improved sense of well-being for people with chronic illnesses or impairments because support group members can offer each other information and help each other cope with difficulties. Support groups offer those aging with impairment a way to learn from each other, learn about health problems and treatments, and form social networks made up of peers (Turner, Grube, & Myers, 2001; White & Dorman, 2001; Wright & Bell, 2003).

Braithwaite, Waldron, and Finn (1999) found in their content analysis of an online support site for people with disabilities that contributors would reassure

each other and boost each other's self-esteem. Although the researchers did not address gender, other research shows that gender makes a difference in online support. Studies of online support groups for people with chronic illness or disease show that women participate and make online contributions far more often than men (Klemm, Hurst, Dearholt, & Trone, 1999; Mo, Malik, & Coulson, 2009; Stone, 2007b).

The participants in research by Thornton and Lea (1992) on people with MS found that face-to-face support groups were most beneficial after the diagnosis. Most of the participants felt that those who were recently diagnosed with MS should be encouraged to meet others with MS and talk about what to expect. Unfortunately, many feared going to support groups provided by the MS Society because of what they might encounter at the meetings. Some reported feeling depressed after seeing people who needed to use a wheelchair, or feeling resentment towards people who had fewer limitations or, alternatively, more visible problems. One person reported being discouraged from attending support group meetings by a physician who advised that the person would find them too depressing. These examples show that although support groups can be beneficial, not everyone is likely to attend or to find them helpful.

Volunteering can be understood as “fundamentally a socially supportive activity” (Gottlieb & Gillespie, 2008, p. 402), and “older adults who proffer help and support to others may enjoy better health and greater longevity because being useful to others instills a sense of being needed” (p. 403). Indeed, evidence is accumulating which shows that when people volunteer their time to help others, health benefits are demonstrable (Li & Ferraro, 2006). At the same time, differences abound in terms of who is able to participate in volunteering. Thoits and Hewitt (2001) showed that volunteers are likely to be better educated, have higher self-esteem than others, and be socially integrated: “[w]e have evidence here of a positive cycle of selection and social causation processes” (p. 127). As Li and Ferraro succinctly stated, “volunteering may have health benefits, but health problems can also determine the level of volunteer participation” (p. 500).

In sum, there is considerable evidence that social support is vital for the well-being and quality of life for people who are aging with long-term physical impairments. However, as mentioned, not everyone has access to a supportive social network in general or a supportive spouse in particular, and there are also gender differences. In addition, the literature contains fleeting suggestions that middle age may have a characteristic or quality that makes it difficult to find or utilize adequate support. The present research, therefore,

investigates gender differences in access to social support for a small sample of middle-aged people who are aging with significant physical impairments.

Methods

The data came from the first author's postgraduate research (Casey, 2008), which explored the coping mechanisms used by people who are aging with significant long-term physical impairments. Given the research interest in people's subjective experiences, qualitative research methods were deemed suitable. A small sample of participants was sought who were between the ages of 50 and 65, had lived with a significant physical impairment for over 15 years, lived in their own home, and spoke English. As well, it was hoped to have an equal representation of men and women with a variety of impairments. The research was approved by the Research Ethics Board of the author's university.

Participants were recruited using two methods. First, family, friends, and colleagues were asked to suggest potential candidates who fit the inclusion criteria as outlined. In this manner, six potential participants living in northern and southern Ontario were identified and agreed to participate in the research. Second, an organization that provides assistance to people with physical impairments was asked for help with identifying potential participants. An organizational representative identified and approached four individuals who she felt matched the criteria and would be interested in participating in the research. After a follow-up phone call from the researcher, however, it was found that only two of the four were available to be interviewed.

The resulting sample consisted of four men and four women (see Table 1), all of whom were Caucasian. Six participants were married at the time of the interview, one was a widow, and one had never married. All of the participants either lived with family members (mostly spouses), or had family living nearby. All but one participant had children, all of whom were over 20 years of age. Four participants had education past the high

school level, three had not gone beyond high school, and one had only completed grade 10. Two participants were employed at the time of the interview; the rest were unemployed. On average, participants estimated their annual income to be between \$20,000 and \$30,000.

Two participants had impairments from MS, two from rheumatoid arthritis (RA), one had lost a limb, one had muscular dystrophy (MD), one had hip deterioration since age twelve as a result of Legg-Calvé Perthes Syndrome, and one had polycystic kidney disease (PKD). The participants aging with MS required the use of a wheelchair on a regular basis, although one of them, Carol (all names are pseudonyms), did not own her wheelchair. Consequently, Carol was physically dependent on others to carry her from room to room inside her own home. The participant with MD used either a rollaid or a wheelchair to assist with mobility. The other participants did not use assistive devices for mobility.

Each participant was interviewed once by the first author, who was trained and experienced in conducting qualitative, in-depth interviews. A semi-structured interview guide was used to elicit comments on issues including impairment-related experiences, health status, the availability of social support, and need for assistance. The interview guide was developed by both authors after conducting a literature review to determine what people who are aging with long-term physical impairments might experience during their life and what they may worry about as they age. Questions related to social support and assistance included these:

"Can you discuss your support network during the aging process? Who have you relied on for support and care?"

"Has your support network changed over the course of your life? How so?"

"Do you experience any problems with your assistance?"

The participants were encouraged to expand on their experiences and were asked more-specific questions

Table 1: Participant characteristics

Pseudonym	Impairment/Chronic Illness	Age at Interview	Years with Impairment	Marital Status	Children	Uses Mobility Aids
Dorothy	Rheumatoid Arthritis (RA)	63	15	Single	No	No
Carol	Multiple Sclerosis (MS)	51	31	Widow	Yes	Yes
Victoria	Rheumatoid Arthritis (RA)	54	Approx. 20	Married	Yes	No
Karli	Multiple Sclerosis (MS)	59	32	Married	Yes	Yes
David	Muscular Dystrophy (MD)	65	28	Married	Yes	Yes
Jake	Polycystic Kidney Disease (PKD)	56	56	Married	Yes	No
Mark	Legg-Calvé Perthes Syndrome	59	48	Married	Yes	No
John	Amputated Arm	56	28	Married	Yes	No

depending on their marital status and family background. For example, a married participant might be asked about how his or her spousal relationship has changed throughout the life course.

Each participant chose the location for the interview, only two of which occurred outside of the participant's home. One participant was interviewed at a coffee shop and the other at a hospital while he was receiving dialysis treatment. Each interview lasted from one to four and a half hours, with most lasting one and a half hours. Each interview was audiotaped with the participant's consent, transcribed verbatim, and analyzed for qualitative themes.

Following transcription of the interviews and to assist with data management, the interview transcripts were imported into QSR's qualitative data computer program NVivo. In consultation with the second author, the first author read and re-read the transcripts several times looking for common themes. The goal of this inductive content analysis was to look "for similarities and dissimilarities – patterns – in the data" (Berg, 1995, p. 60). Open coding was used to reduce and make sense of data and to identify common themes. That is, the transcripts were read "line by line and word by word to determine the concepts and categories that fit the data" (Strauss, 1987, p. 28). This coding process was iterative; in consultation with the second author, who reviewed portions of all transcripts, the first author continually revised the codes by going back and forth between the transcripts and the codes, seeking conceptual clarity. In other words, the coding and analysis were accomplished primarily by one author, but at all times in close consultation with the second author.

Findings

Generally, participants believed their experiences of aging with long-term physical impairments were improved when they shared their thoughts, feelings, and problems with others. Participants' experiences with social support are examined under the sub-headings of *Family and Friends*, and *Support Groups*.

Family and Friends

Almost all research participants credited much of their ability to cope with a physical impairment to having supportive family and friends.

Women's Experiences

Dorothy was the one participant who had never married or had children. An indication of how important supportive family can be was revealed in Dorothy's comment that she could look back to the start of her

RA symptoms and link her recognition of a problem to her brother's death. That is, Dorothy believed that her RA was triggered by the stress she experienced while watching her brother die from cancer. She had been close to her brother, who had lived with his wife in a house attached to Dorothy's. Since his death, she has remained closely connected to her brother's family, as her nephew and his family moved into her brother's home. In discussing her close family connections, Dorothy expressed relief that her nephew moved into her brother's house, and that, even though her sister-in-law moved approximately forty minutes away, the sister-in-law nevertheless continued to stay in touch and help Dorothy.

Dorothy's sister-in-law drove her to doctor's appointments and invited her for meals. Dorothy was grateful for this, yet worried that the distance between their residences created too much of an inconvenience for her sister-in-law. Within the context of expressing this worry, Dorothy made it clear that she wanted to be able to offer as well as receive support, yet the geographical distance between them meant that this was difficult to do. It had been easier for Dorothy to reciprocate in terms of social support when her sister-in-law had lived next door.

On an emotional level, Dorothy felt that it was a comfort to know that she had family members and friends to rely on for instrumental support. Thus, the provision of instrumental support was simultaneously experienced by Dorothy as emotional support. Indeed, she felt that she had a high quality of life and attributed this to having a number of supportive friends and family members. In Dorothy's words:

In my case now, you know, I guess having supportive friends and family ... certainly my niece – helps me, a lot. My sister-in-law's sister: she's wonderful. She comes in and trims shrubs and takes me to town when she's not working.

The other participant who was single at the time of the interview was Carol, who was severely impaired due to MS, and who became a widow two years prior to being interviewed. Nonetheless, Carol said that she had not felt supported by her husband before he passed away. She briefly explained that he had not been helpful. After he had been forced to retire early, owing to failing eyesight, from employment as a truck driver, he would sit on the couch and drink a "26er" every day. As a widow, Carol relied on her two adult sons who lived with her to care for the home and carry her from her living room chair to the table each night. Other assistance came from personal support workers who provided light housekeeping and attended to Carol's personal needs, such as bathing and dressing. Carol's mother came to visit every afternoon and brought her

a coffee. Her siblings, who mostly lived nearby, offered help whenever needed. Carol's sister, for example, took her to doctor appointments and organized renovations to her bathroom. Altogether, Carol felt that she received a considerable amount of instrumental and emotional support from her family.

All other participants were married and living with their spouse at the time of interview, although not all of them experienced emotional support from their spouse. This was the case for both Victoria and Karli, who said that they often felt alone.

In Victoria's case, she was aging with RA. When asked about her support network and who listened to her problems, she said "Really, I have nobody." After some discussion about needing assistance with physical tasks, Victoria mentioned that her family members were helpful, but that she had no one to talk to about her feelings and experiences. She said that she sometimes thought that her husband just would not understand. The one person to whom Victoria felt comfortable talking was her internist. She explained:

He listens to what you have to say. But to just sit and talk to somebody – I don't talk, really, to anyone about my health. People say, "How are you?" And I could be having a real bad day and I tell them I am doing good. That's one thing I read in the book, a book that says that people with rheumatoid arthritis will say that they are doing good even when they aren't and, boy, that's me.

Victoria further explained that she liked to keep her personal struggles to herself and tried to hide her limitations because she did not want others to feel sorry for her.

In contrast, Karli, who was aging with MS and who used a wheelchair, spoke affectionately about her relationship with her husband and said that although their relationship was not always perfect, she was happy. She said that he

puts a roof over our head, [takes care of] clothes, food to eat, the bills keep getting paid – everything just keeps coming. We eat. [pause] He provides for all my needs to survive. And on top of it all, he loves me and every now and then reminds me that I am his princess. [pause] I don't need to be cuddled by people. I wouldn't have wanted that. I think I would have felt smothered.

Nevertheless, Karli did not feel that her husband entirely supported her emotional needs. In particular, she felt that he did not understand her need to stay in touch with her birth family, and she wished that he were more supportive of her need to telephone family members. With most of Karli's family living in the United States rather than Canada, she relied primarily

on the telephone and the Internet to remain in contact. Unfortunately, she needed to rely on phone cards to call her daughters, siblings, and mother, and she needed a phone card that would help her to dial the complex access code, because she could not always do it herself. At the best of times, it was quite inconvenient for Karli to use a phone card, and she was often unable to talk to her family members. Karli was not sure why her husband would not set up a long-distance calling plan so that she would not have to use a phone card, and she seemed unfamiliar with the state of household finances in general.

By and large, Karli managed with her impairments because she received assistance from agencies in her community. According to Karli, the agencies determined the amount of assistance she required on the assumption that her husband would provide a basic level of support. Karli explained that although she could use more hours of support, especially at night as she prepared for bed, the agency had determined that her husband could help her prepare for bed each night. At the time of the interview, Karli's husband had to lift her onto the bed, but he found this very hard due to his own difficulties with a weak back. Still, Karli and her husband had no choice but to struggle as best they could, as they were not entitled to additional hours of help from community supports. Karli seemed reluctant to ask her husband for help unless she was really having a hard time; she took pride in being "pretty independent for somebody who can't work their chair properly." She acknowledged that she could continue living in her own home only because her husband helped her, but she still tried to hide her problems from him.

Karli enjoyed being busy, and even before being diagnosed with MS, she had been actively involved in her community. Her volunteer work in the community, and especially the volunteer work for the church that she joined after becoming disabled, gave her a sense of usefulness. Moreover, Karli became friends with a number of people who were happy to spend time with her, providing her with emotional support and companionship. She very much enjoyed laughing and joking with her friends, and her friendships allowed Karli to remain upbeat about her life.

Men's Experiences

Unlike the female participants, male research participants appeared to rely upon their spouse for emotional support. Two did not talk about looking outside the spousal relationship for emotional support. The other two, although they discussed having support outside the home, also enthusiastically described the tremendous emotional support they received from their wives.

David, who was aging with MD, found it difficult to leave the house. He could never be left alone because there was a high risk of his falling or choking. He relied primarily on his family for support, although he also received a few hours of daily nursing care from an agency. Although he mentioned that he sometimes participated in a day program called Senior Support, which allowed his wife some respite from offering instrumental support, he did not comment on whether he enjoyed his day away from home. He had special praise for his wife who not only provided him with emotional support but who had also taken on many responsibilities around the home. David said that he worried about her because he felt that there was a lot of pressure on her to do things. Beyond this, David did not comment on his relationship with his wife. David's adult children were also supportive and assisted their mother as much as possible in caring for David's needs. Since he did not mention anyone else offering him support, it appears that he did not look outside the home for emotional support. He seemed to be more concerned about his wife's emotional well-being than about his own.

Jake, who had had PKD since birth and who had spent 14 years going to the hospital thrice weekly for kidney dialysis treatments, was another participant who had little to say about whom he turned to for emotional support. While he said that his wife and son were what kept him going, thus implying that he looked to them for emotional support, he also talked about not wanting to rely on them for help with physical tasks. Indeed, he went so far as to say:

I have often told my wife and son, if something happens that I have to end up in a wheelchair and you have to look after me, then that's the end. No more dialysis. I don't want you to spend the rest of your life looking after me because I can't look after myself.

He made it clear, in other words, that becoming a burden on his family was something to be feared more than death. He believed that his wife had a hard enough time as it was, coping with a husband who was dependent on frequent dialysis and deteriorating physically. Like David, he seemed to be more concerned about his wife's well-being than about his own.

Mark, who was aging with a deteriorating hip due to Legg-Calvé Perthes Syndrome, expressed worry about the emotional strain that his impairment was putting on his wife. Unlike David or Jake, Mark openly discussed how he was able to cope with his impairment. In this regard, he said that the emotional support he received from his wife and children was vital. He also talked about the important role played by his religious faith in helping him to cope emotionally. However,

Mark's comments were similar to David's and Jake's in that he expressed considerable concern for his wife's emotional well-being. He said: "My wife, she was [pause] always been strong but I could tell there were times when emotionally she was drained to the max."

Mark was also interested in remaining involved in his community as much as possible. He spoke enthusiastically about acting as umpire for his children's baseball games and about coaching his children's soccer team – volunteer activities that allowed him to be involved in sports and the community without putting too much strain on his hip.

John, who had been living with an amputated arm for several decades, discussed at length the significance of emotional support. He said that he often relied on his wife for both emotional and physical support, although he was alone among the male participants to say that he consciously tried not to take up too much of her time because she had her own life. In this regard, he said that his physical therapist recommended that he get his wife to help him with his daily exercise routine, but he said:

It's just, she's doing other stuff, you know. [pause] I don't feel like I can say, come here and do this with me every morning, you know. So, on the one hand you go, Geeze, I really wish she would [help with my exercise] because this would be good for me, but she is not here just to serve my needs.

John was also the only male to talk about having close friends to rely on for emotional support, and he was also the only participant to talk about having these friends in addition to a supportive marital relationship. Like Mark, John was also involved in his community: he volunteered a considerable amount of time to offer support to injured workers, and he was very involved with injured workers' organizations to improve the legislative environment regarding compensation for work injuries.

Support Groups

Support groups can offer both informational and emotional support. Three participants had experience as members of a support group, but only one – John – belonged to a support group (a group for injured workers) at the time of the interview. John said that he was often the one offering information, advice, and support, but that he also benefited from his conversations with others. He strongly believed that support groups were beneficial for people.

Dorothy said that she used to attend an arthritis support group but she quit going because it became too much of "a hassle in the winter time; it was more of a hassle to attend [compared to] what you got out of it."

Dorothy had especially enjoyed attending the support group to hear other people with arthritis complain about able-bodied people offering suggestions on how to improve their life. The complaints of others served to reinforce Dorothy's own belief that able-bodied people, however well-meaning they might be or supportive they might think they are being, did not have the moral right to offer advice to those who lived with impairment. In her words:

People want to give you advice – “Well, it's easier to do it this way”. Well, when you are not disabled, how do you know that it's easier for me to do it this way? So I think, sometimes, unsolicited advice really bugs me.

Dorothy said that she would have liked to return to the group, but felt that the challenge of leaving her home would not make it worth the effort of going.

Karli, the only other participant with experience attending a support group, was well aware that support groups can be very beneficial, especially for people with physical impairments. Indeed, Karli started a support group in the small town where she had once lived. Her group was focused on making the town more accessible to wheelchair users, and by way of her work as a disabled rights activist, she created a built-in support group for herself and others.

Karli, however, no longer lived in that town and at the time of the interview had difficulty leaving her home. Consequently, she was no longer involved in a support group. Nevertheless, Karli was quite computer literate and spent a good part of her days contributing to several Internet discussion boards. These discussion boards were related to her interests (NASCAR racing and reading books) rather than to her physical impairments, yet they met her need to feel connected to others.

Those interview participants who had no experience with support groups were vaguely aware of their existence but for various reasons were uninterested in attending. Some said that the groups were not convenient to attend, while others said they did not want to talk about their problems or hear about others' problems.

Discussion and Conclusions

The importance of social support for maintaining or enhancing a sense of health and well-being when living with health challenges is well established in the literature (e.g., Cohen et al., 2000; King et al., 2006). Support, which can come from family members, friends, and/or support groups, involves more than assistance with physical tasks (i.e., instrumental support). It is important for adults aging with long-term impairments to know that there are others they can turn to for help on an emotional level, and it is impor-

tant for them to have access to the information they need in order to cope with physical impairments.

Unless a person has a strong network of family and friends available for emotional support, coping with long-term physical impairment can be a lonely experience. Evidence of this could be seen in the case of Victoria; although she was married, she did not feel able to talk to her husband about her experiences. Indeed, she talked to no one but her internist. No one else in our research study appeared as emotionally isolated as she did. Although the other married women also spoke of being unable to look to their husbands for emotional support, they had other people to whom they could and did turn. As well, all of the men seemed to feel that they were emotionally supported. Two implicitly commented on being able to turn to their wives for emotional support, and two explicitly commented about their emotionally supportive marriages in addition to supportive relationships in the community. Meanwhile, the only never-married participant talked at length about how many people she could turn to for support and how this contributed towards her high quality of life.

The married women's experiences with lack of spousal support reinforce the point that marriage is not necessarily, and should not be assumed to be, a protection against emotional isolation. In order to determine whether married people feel supported, it is important to pay attention to the subjective assessments made by each marital partner. This point, although made in a number of studies (e.g., Allen et al., 1999, 2000; Ballantyne et al., 2001; Birditt & Antonucci, 2008), remains underappreciated by policy makers and members of society who often assume that married people are receiving care.

Moreover, it was precisely because of the assumption – on the part of agencies, for example – that spouses are available and capable of supporting each other that some research participants had unmet support needs. In particular, Karli was denied access to extra support services because of the agency's assumption that her husband would help her, while John was assumed by his physiotherapist to have unlimited access to his wife's time for help with exercises. Social-policy makers and those in the health professions must recognize that regardless of whether someone is married, not everyone is willing or able to ask for help from a spouse.

It might be argued that people who do not have ready access to social support from family or friends should be able to turn to a support group to find empathy, sympathy, or understanding regarding what it can be like to age with chronic impairment. Yet, few participants in our research were interested in turning to

support groups for information or emotional support. Thus, although there is evidence in the literature (Braithwaite et al., 1999; Klemm et al., 1999; Mo et al., 2009; Stone, 2007b; Thornton & Lea, 1992) of the benefits of peer support for people with impairments, it is clear that not everyone believes peer support would be helpful for their sense of well-being. Moreover, the literature notes that women are more likely than men to turn to a support group for emotional support, a finding we made in this research.

The literature on disability and chronic illness pays more attention than the literature on aging to the ways in which gender influences how people seek support and who they seek it from (e.g., Allen et al., 1999; Ballantyne et al., 2001; Charmaz, 1994; Gibbs, 2005; Harrison et al., 1995; Pentland et al., 1999, 2002; Solimeo, 2008; Zakowski et al. 2003), and our research reinforces the finding that married men are more likely than married women to seek emotional support from a spouse. All but one of the male participants in our research discussed the strain they were placing on the marital relationship as a result of looking to their wives for support, and all expressed concern for their wives' well-being. Their concern stands in sharp contrast to what was (not) said by the married female participants, none of whom commented about being worried that their husbands were being overwhelmed by supporting them. Indeed, they commented on not looking to their husbands for support, which suggests that they were cognizant of the importance of maintaining the integrity of the marital relationship and, for this reason, were reluctant to strain it more than absolutely necessary. Consequently, the women were likely to look outside the marital relationship to find ways of meeting their social support needs.

More generally, our findings underscore the broader point that individuals aging with impairments are immersed in and wish to maintain reciprocal relationships. This is evident from the comments offered by all participants, regardless of whether they felt they had adequate levels of social support. Both male and female participants discussed concerns about causing stress for family members by asking for too much help. They did not want to be a burden, often preferring to do things independently as much as possible, or obtaining help from paid support workers. John, who apparently experienced a great deal of support from his wife as well as from his friends, showed his interest in maintaining his marital relationship when he said that he did not want to impose his needs on his wife. Similarly, Dorothy felt quite supported by her family, yet worried that she was inconveniencing them too much. Victoria, the participant who felt the least degree of support from anyone, was nevertheless interested in protecting her husband from knowing how difficult it

was for her to cope with having RA. Each participant, in his or her own way, showed awareness of the importance of maintaining the integrity of relationships with others. Rather than see themselves as incapable of engaging in social relationships, they viewed themselves as having something to offer others, and to function as full members of society.

One way to be recognized as contributing to society, of course, is to be engaged in volunteer work in the community. As we have noted, volunteering is "fundamentally a socially supportive activity" (Gottlieb & Gillespie, 2008, p. 402). Three of the eight participants – Karli, Mark, and John – spoke about the importance in their lives of volunteering, and all three benefited emotionally as a result of their volunteer activities. Significantly, these three were the best-educated participants in our sample, and all three appeared to have a high sense of self-esteem. Unfortunately, neither Karli nor Mark was able to volunteer as much as they would have liked due to their physical limitations. Thus, our research sample mirrors the findings of other researchers with regard to who is likely to volunteer and thus reap the health benefits from volunteering (e.g., Li & Ferraro, 2006; Thoits & Hewitt, 2001).

Finally, it must be emphasized that although these findings are based on a small and unrepresentative sample, they are suggestive of issues and concerns that may be found for a larger population. As the baby boom generation ages and people live longer, it will become even more common for people to age with long-term physical impairments. This is an area that requires more research attention to ensure that the needs of this population are met. More awareness is needed to ensure that people aging with long-term physical impairments have access to social supports that meet their needs. Otherwise, the assumptions that all people will benefit emotionally or physically from living with a spouse or that all people benefit from joining support groups will, ultimately, result in a less than satisfactory level of support for those aging with a long-term physical impairment.

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