

## Scientific Review

### Women with spinal cord injury and the impact of aging

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**Objectives:** The objectives of this study were to describe what women with longstanding spinal cord injury (SCI) feel they are experiencing as they age, how they are coping and what they require in order to ensure their continued social and economic participation in society.

**Study design, methods and setting:** A naturalistic approach was taken, incorporating three focus groups ( $n=10$ ) and key informant interviews ( $n=19$ ) of women with SCI ranging in age from 31 to 70 years and living in rural and urban communities in Ontario, Canada.

**Results:** The women feel isolated and sense many of their key concerns are ignored or dismissed by health care and service providers. The common physical changes and concerns were gynecological/sexual and bowel and bladder issues. Socio-emotional changes with age included impact of their age-related changes on important relationships and re-evaluation of personal priorities. They articulated worries including declining health, increasing dependency and financial stresses. Additional resources they need to age successfully include improved environmental accessibility, assistive devices, more flexible and responsive attendant and household support, access to recreation and fitness opportunities and peer and psychological support.

**Conclusions:** Many of the issues raised by the women were consistent with the authors' previous examination of aging in men with SCI and women with disabilities. The most striking difference was their profound sense of isolation and perceptions that health care and service providers were unprepared or unwilling to address the unique issues they face as women living and now aging with SCI.

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#### Introduction

Roughly 80% of spinal cord injuries (SCI) are sustained by men. As a result, research has historically rarely focused specifically on the needs and issues of the remaining 20% of persons with SCI, who are women. Both research and lived experience tells us that men and women in the general population experience aging very differently. Previous research by the investigators on aging in women with a variety of long-term disabilities reveals some of their unique issues and concerns.<sup>1</sup> However, none of the subjects had spinal cord injury. Based on the authors' previous work on aging in men with SCI, and their experience examining aging in women with life long disabilities in general, there is clearly a need to examine the unique

age-related issues and concerns for women aging with SCI.<sup>1,2</sup> This information is essential for women with SCI to plan and prepare for their later years. It will be an important resource to guide policy, consumer, and community groups. It will also inform service delivery and research that is committed to enabling women with SCI to continue contributing to and participating in society throughout their lifespan.

The available research on persons aging with a disability has been based largely on male or male dominated samples.<sup>2–14</sup> Research in various fields has established a myriad of significant differences between men and women, including: how they cope with disability; and how they age; all suggesting that studies of the impact of aging on males with a disability cannot be generalized to disabled women.

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### *Gender differences in aging of the general population*

Gender differences in the general population's response to aging suggest excess gender-related risks for women aging with a disability. These differences include:

- women's approximately  $7\frac{1}{2}$  year longer lifespan;<sup>15</sup>
- older women's poorer perceived health;<sup>16</sup>
- greater risk of depression;<sup>17</sup>
- greater use of psychoactive medication;<sup>18</sup>
- higher risk of poverty;<sup>19</sup>
- greater expressive bonds;<sup>20,21</sup>
- the greater impact of negative health events on women who live alone;<sup>22</sup> and
- the decreased likelihood of living with a spouse (77% males vs 24% females) and thus having the associated supports and companionship.<sup>23,24</sup>

### *Gender differences among persons with disabilities*

There is a paucity of information about the lifestyles of women with disabilities and the personal or environmental resources and barriers to healthy and satisfying behavior.<sup>25</sup> What exists is based on very small samples and originates in the USA and Europe where health care policy and social services differ markedly from Canada. In 1981, Fine and Asch<sup>26</sup> were among the first to argue that disabled women were more disadvantaged than either non-disabled women or disabled men, and called for new directions in research and policy. Recently a small number of anthologies about the experience of women with disabilities have been published,<sup>27-34</sup> all revealing that they are disadvantaged in many dimensions of daily life. Women with disabilities have been shown to be more likely than disabled men to be denied access to culturally and age appropriate roles in families, education and employment, to have more difficulty accessing health, rehabilitation and financial assistance and to be unmarried, stigmatized, devalued, and treated less humanely.<sup>35-38</sup> Findings such as these have led to the label of 'doubly disadvantaged' (woman plus disabled).

Married elderly are 'advantaged'. They have higher incomes, morale, life satisfaction, mental and physical health, social integration and social support. They do not need to rely as much on formal support services, and have lower rates of institutionalization.<sup>39,40</sup> Since marriage rates for women with SCI are substantially lower than for the general population or disabled men, it is likely that a larger proportion of women than men with SCI will face the aging process alone, either because they have lived alone for years, or their husbands have divorced or pre-deceased them.<sup>41,42</sup> Reduced financial security has been shown to have a negative impact on successful aging.<sup>43</sup> Women with disabilities are less likely to have the financial supports associated with being married,<sup>44</sup> and are less likely to have been employed than either disabled males or non-disabled females, and thus receive retirement benefits.<sup>45</sup> In the 1986-87 Health and Activity Limitation

Survey (HALS), disabled women cited 'cost' and lack of assistance (which normally costs money) more often than disabled men as a barrier to participating in activities.<sup>45</sup> The findings may not be surprising in light of a study of the socio-demographic characteristics of the physically disabled in Canada that showed them to be generally older, female, and more likely to be divorced, widowed, or separated.<sup>44</sup> All of these factors are frequently associated with poverty in the general population.

### *Aging with a long term disability*

We are only beginning to understand the interactions of aging and pre-existing disability. There has been only limited speculation as to the nature and quality of resources needed to age with a disability.<sup>46-48</sup> The focus of research has been on mortality, morbidity, and physical pathology. Only relatively recently have other aspects begun to be examined such as the social, behavioral, and economic changes, or perceptions and concerns that accompany aging.<sup>49</sup> Our previous examination of aging in men with spinal cord injury we found that with increasing age, the sample experienced more fatigue, decreased activity (due to pain) but, at the same time they reported greater life satisfaction.<sup>2</sup> We also found that with aging and duration of SCI amplified male subject's perceptions of financial security and threats to health.<sup>2</sup>

Based on case studies, Trieschmann<sup>46</sup> hypothesized that the coping resources of persons with disabilities may already be stretched to the limit by the demands of daily life. In such a situation, the increased demands of aging (adapting physically, psychologically, economically, etc.) could be the 'straw that breaks the camel's back'. Conversely, these individuals might actually be better prepared to adjust to aging because they possess special coping resources, (developed to cope with and adjust to the disability itself). These two opposing views are very similar to competing hypotheses found in the literature on aging among minority populations. The 'double jeopardy' hypothesis<sup>51-53</sup> is to be contrasted with the 'age as leveller' hypothesis.

In the 'double jeopardy' view, minority status and other factors such as income, age, and gender, separate people into groups with unequal access to societal rewards. There are 'additive (or multiplicative) negative effects'<sup>52</sup> of membership in more than one disadvantaged category. In other words, women + disabled + elderly = 'triple jeopardy'.

Conversely, the 'age-as-leveler' hypothesis proposes that age 'levels' differences found in earlier life stages between majority and minority (or otherwise disadvantaged) populations. This occurs, for example, because of the 'levelling' impact of poor health and widowhood, experiences that cross class and ethnic boundaries. Both of these hypotheses have found some empirical support in research,<sup>53</sup> with the double jeopardy perspective better supported by objective

indicators, than subjective indicators. While neither hypothesis was directly tested in the present study, they help to provide a theoretical background for the project and findings.

The literature suggests that the aging experiences of women with spinal cord injury will differ from both men with, and women without, disabilities secondary to numerous factors. It is still not clear which resources they develop and require, and whether the aging process further disadvantages them, or acts as a leveller by calling on previously developed coping skills. To our knowledge, this study is the first to examine aging with a spinal cord injury specifically in women.

## Methodology

Since this was an initial examination of the topic, we used a qualitative approach involving three focus groups ( $n=10$ ) followed by key informant interviews of 19 women with SCI. Focus groups allow for direct interaction with respondents, provide rich data in participants' own words, and are regarded as particularly appropriate for topics such as this where little is known about the area. The synergism of the group interactions can uncover data or ideas that may not arise in individual interviews.<sup>54-56</sup> The focus group reveals how the respondents view and talk about the phenomenon, and the findings can be used to generate research hypotheses and instruments for future quantitative testing.<sup>55,56</sup>

Key informant interviews on the other hand provide a more intimate, detailed account of aging with a spinal cord injury and can be used to explore some of the issues generated in the focus groups. The use of the two data collection techniques enabled access to a broader sample of women with SCI, including those living in more rural locations or northern towns and cities.

## Participants

Participants were recruited through the Toronto Rehabilitation Institute (Lyndhurst Centre) database and West Park Hospital in Toronto, Canada. Lyndhurst is a regional spinal cord rehabilitation centre in central Ontario. Its database includes information on all individuals receiving rehabilitation for SCI over a large geographic area since 1945. We decided to recruit from West Park Hospital also, as it enabled us to include women who have sustained high level quadriplegia (which necessitates ventilator use). Persons with lesions this high do not receive rehabilitation at Lyndhurst.

Women were contacted in order of age, with the eldest being contacted first. There was no 'cut-off' age however, since both the literature and the investigators' previous works suggest persons with disabilities may experience some premature age-related changes. The sample is described in Table 1.

**Table 1** Description of the participants

Age	Mean = 50 years. Range = 35–70
Duration of SCI	Mean = 12 years. Range = 3–38
Lesion levels	Cervical = 10 Thoracic = 17 Lumbar = 2
Marital status	Common law/married = 15 Single = 6 Separated/widowed/divorced = 8
Employment status	Not employed = 20 (incl 4 full time caring for own children) Part-time = 4 Full-time = 5
Education	High school = 7 College = 7 University = 15
Income	< \$15,000 (CDN) = 6 \$15–25,000 = 4 \$25–35,000 = 5 \$35–50,000 = 4 > \$50,000 = 6
Satisfaction with income	Very unsatisfied = 3 Not satisfied = 4 Some difficulty = 2 Adequate = 9 Very satisfied = 10
Mobility	Walk (incl. cane) = 7 Manual wheelchair = 10 Manual and power chair = 8 Power chair = 4
Living situation	Alone = 4 Spouse = 15 Other adults = 5
Life satisfaction score	Mean = 6.7/10

## Data collection

A qualitative approach was taken to answer the research questions since the study sought to understand the respondents' perspective in its totality, rather than attempting to make their experience correspond to preconceived theory or structure. The technique known as Explanatory Models was employed to collect information on the participants' perceptions of aging. This approach was developed by Kleinman<sup>57</sup> to study the effect of culture on perceptions and attributions of illness. It was used to uncover the mental or conceptual maps that people use to understand illness. Explanatory models captures the idiosyncratic cognitive and affective experience of individuals relative to certain personal phenomena. The Kleinman questionnaire has been adapted to serve a variety of purposes and has been used previously in studies of disability.<sup>58-60</sup> McColl *et al*<sup>60</sup> adapted the Kleinman model to study aging in spinal cord injured men. The Kleinman questionnaire was adapted for this study and served as a guide for both the focus groups and key informant interviews. Since the same interview questions have been used previously with disabled males, it was

possible to do some cross-gender comparison of the findings.<sup>11,60</sup> Demographic data (nature and duration of disability, year of onset, age, living situation, children, education, employment history, household income) were collected from all participants.

#### *Focus groups*

Three focus groups of 4–7 women with SCI were held; one in Toronto, one in a smaller northern Ontario city and one by teleconference. This latter enabled women living in outlying areas to participate. The focus groups lasted approximately 1½–2 h.

The focus groups were conducted following guidelines from Stewart and Shamdasani<sup>54</sup> and Krueger.<sup>61</sup> Considerations include use of a moderator with suitable personal characteristics, training, interviewing skills, and a thorough understanding of the research problem. Additional factors include creation of a non-threatening, non-judgmental atmosphere that ensures free expression and full group participation. A moderator approach that falls between the directive and non-directive approach was used to ensure the discussion moves along, while allowing opportunity for participants' views to emerge, and reducing tendencies for the moderator imposing preconceived framing of the issues. In recognition of the potential for moderator bias, each focus group had two moderators. Moderator intimacy with the group has the advantage of increasing openness and discussion, but introduces the danger of biasing responses, the use of two moderators was seen as particularly valuable. The focus groups were audio-taped and later transcribed verbatim. The moderators' field notes were used during analysis to help develop the coding system.

#### *Key informant interviews*

Key informant interviews of ¾ to 1½ h were conducted by telephone with 19 women living across Ontario. They were audio-taped and later transcribed for analysis.

### **Analysis**

All focus groups and interviews were audio-taped and transcribed. Approximately 500 pages of text were generated. One focus group transcription and one key informant interview transcription were circulated to the investigators to examine for themes. Then all of the investigators plus the research assistant met to develop a coding system corresponding to each of the research questions. The unit of analysis for coding was thematic; the thought, idea, or concept expressed by the participants. The process of developing the coding system was iterative whereby increasing consensus was established as to the meaning and range of each of the codes.<sup>62–64</sup> Once the coding system was established, analysis was descriptive and carried out using QSR

Nvivo which is software for the analysis of qualitative data.<sup>65</sup> This allowed us to begin to uncover the conceptual maps that women with SCI use for understanding aging and disability, and the resources needed to age satisfactorily.

### **Findings**

The objectives of the study were to identify age-related changes reported by the women with spinal cord injury, their worries and concerns, the strategies and resources they find useful and what they feel they need to age successfully.

Under these headings in Table 2 are listed the most common themes, in descending order based on the frequency that the women mentioned them. In other words, the most commonly mentioned theme is listed first.

The women's descriptions of the impacts of aging centred around physical and socio-emotional changes they were experiencing. There was near consensus among them that it was the physical changes that appeared first and these in turn precipitated emotional, social and lifestyle changes.

#### *Physical changes*

Five themes emerged in the area of physical changes. Table 1 ranks these in order of frequency, with most frequent first.

*Gynecological and sexuality issues* These predominated. It became clear that these concerns had not necessarily been precipitated by aging, but have existed since the onset of the women's SCI.

The women expressed a great deal of anger and frustration about the lack of information, support and knowledge about the particular needs of women with SCI and gynecological health. A number of comments were made on menstruation. They reported that menstrual flow becomes heavier with age, and wheelchair transfers cause 'flooding' by creating surges in menstrual flow. They indicated that ovulation often creates symptoms of bladder infection; and a typical frustrating cycle of diarrhea associated with menstrual periods that resulted in frequent 'accidents' followed by a urinary tract infection. This, in turn, has to be treated with antibiotics, which have their own drawbacks. They may lose effectiveness with over-use, and tend to cause yeast infections as well. An unhealthy cycle thus goes into effect.

Many of the women in their early 40s have begun experiencing symptoms that may indicate the early stages of menopause. They state they cannot get clear answers from their doctors about whether these symptoms are appropriate for their age, whether the SCI causes early menopause, whether the shock of the SCI to their system may have precipitated atypical hormonal changes, or whether their medications are affecting their hormone balances. They reported that

**Table 2** Themes that emerged from the women's response ( $n=29$ ) ranked in order of concern

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<i>Physical changes</i>
Gynecological/sexuality
Bowel and bladder
Joints/pain/wear and tear
Fatigue
Skin and appearance
<i>Social and emotional changes</i>
Relationships
Negative emotions
Emotional strength and revised priorities
Premature ageing
<i>Strategies and resources</i>
Mental attitude and behaviour
Informal supports
Formal supports
<i>Worries and concerns</i>
Increasing health problems
Increasing dependency and isolation
Financial worries
<i>Additional resources they need to achieve successful ageing</i>
Assistive devices and environmental access
Attendant care and household assistance
Peer and psychological support
Financial resources
Research and scientific advancements in SCI
Access to recreation opportunities

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'no one seemed to know' the answers to their questions about SCI and menopause:

*'I was taught from the urology clinic resident ... she was female and she said, 'A lot of male doctors – the urologists – don't realize that females are dealing with this as they get older with long term disabilities'. They need to chart and look at their period cycles and see what time of the month. I know my ovulation time because I start to feel like I've got an infection coming down. And 10 days later my period starts.'*

*'As your period starts to become irregular (with menopause), it affects your bowel routine.'*

The women spoke at length about needing information on sex and spinal cord injury. Most of what is available seems to be geared to men. They indicated that even during rehabilitation, their sexuality and intimate relationships were virtually ignored. They reported feelings of isolation and a lack of support for couples regarding sexuality; there is no forum for communication. They expressed profound feelings of deep sadness and loss around their sexuality and sexual

expression. This loss has undermined intimacy and closeness in their relationships:

*'Every study, everything – sexuality – is all on men. You look at women with spinal cord injury and sexuality ... you even look it up on the internet and it's how to have a baby. Guys can have an orgasm but we have to find alternative options as far as written material goes. Guys get to do it. Why can't I? But there's nothing written on that. Everything is about men.'*

*Bowel and bladder changes and concerns* This was the next most common area raised. The women noted with frustration that they are experiencing more frequent urinary incontinence and urinary infections. They reported urinary infections are inevitable whenever they are admitted to hospital. They indicated they had not been educated about the interactions between bowel routines and menstruation. A common problem seemed to be that diarrhea frequently occurs in conjunction with menstruation, leading to bowel 'accidents' during transfers, and in turn to bladder and vaginal infections. The women note they now have increased bowel care needs and attribute these changes in part to the 'wear and tear' of bowel routines year after year (which they describe as a 'violent' procedure), along with constipation from long term pain medications leading to impacted bowel and dysreflexia.

*Musculoskeletal pain and deterioration* This was frequently identified as an increasing problem over time. The women see this as secondary to the interaction of long term wheelchair use and aging. They reported worsening upper limb joint pain causing difficulty in both daily functioning and sleeping. Deterioration and breakage of rods and spinal supports was frequently recounted, with vivid and even gruesome anecdotes. The women reported difficulty finding information on osteoporosis and women with SCI. The women discussed their experiences with increasing pain at length and expressed a sense that the 'pain runs my life', leading to exhaustion, depression, and an endless search for proper pain relief.

*'Everything's wearing out. Um, with elbows, shoulders ... I've got tennis elbow in my right arm that I've had since February and I think that developed from getting a new chair that was really hard to open.'*

*'You come out of rehab with this strong sort of I've got to overcome the disability at all costs type of attitude and exercise is what I must do to overcome it, instead of learning how to compensate for your loss of function so that you can carry on life with efficiency and that the disability doesn't rule your life ... It's more how can we get you to be independent physically doing it yourself as much as possible, we*

*want to normalize you. Instead of saying look, you know you're physically not able to do this, don't worry, someone will help you do it, or there's equipment to make you able to do it so you can get on with the important things in life, but instead the emphasis is on how you can struggle to do this'.*

**Fatigue and reduced energy with age** This was identified by most of the respondents. They find their stamina is declining, and napping is necessary but it is hard to make time for it. The demands of housework and childrearing and occasionally caring for aging parents as well, are becoming increasingly exhausting and made worse by sleep disturbance, depression from feeling so tired, and in pain. The women with quadriplegia identified that just maintaining and administering life with a high spinal cord injury is exhausting. The women agreed that life has an increasing sense of slowness and sedentariness.

*'I'm finding I have to limit myself more now in what I can physically do in a day. It's very discouraging.'*

*'So I'm at an aging point at only my early 40s saying I've got to go either into a retirement living situation or a very small little place because I can't cope.'*

*'Like I've been disabled for most of my life so now I'm aging with this disability and finding my energy levels down really upsets me. I'll look at things on my schedule for that day and know I'm not going to be able to accomplish them ... but I really need to. I find that mentally and emotionally very hard, because I used to be able to do all that but now physically and emotionally I just can't pull myself together to do it.'*

**Skin and appearance changes were reported** Skin vulnerability is increasing with age, and care giving for others (children and aging parents) often causes the women to neglect their own skin maintenance. Concern with weight gain was frequently raised. The women find not only that they gain weight more easily now, but it is harder to lose because they can't be as active due to physical declines and the need to conserve energy. Fatigue, accessibility and pain limit their abilities to exercise. They fear the weight gain, knowing it is a health risk and creates extra stresses on their upper limbs.

#### *Social and emotional changes*

The four themes of changes identified in this area are shown in Table 2.

**Relationships** Themes fell into three categories: relationships with spouse, people in power and parents/children. The women with partners indicated that they are relying on them increasingly for personal care, which changes the dynamics of the relationship, and is perceived as both a threat and loss for both parties.

The women described fearing they would lose or be abandoned by their spouse as they become increasingly dependent and unable to join in activities once engaged in as a couple and family. Many of the women – even those with severe injuries – continue to perform heavy housework (clean own floors and toilets). Those with lower, incomplete, and thus less visible injuries, reported that as they age, they have less energy and more pain, and can do less housework, and the family doesn't always understand. There was consensus that they feel others expect them to be able to continue to function at the level they attained on discharge from rehabilitation. But as they age, they find they just cannot keep up those levels of physical household responsibilities.

The women indicated that as they age they need and are in more frequent contact with social services, insurers and health care. The women feel that the 'people in power' in these systems lack information about women, aging and disability and frequently misunderstand and are unprepared to deal with their issues and concerns. A number of the women described that as they are able to do less with age, they feel a growing sense of isolation from family and peer group.

*'I wouldn't want to have a stroke ... dysreflexia can cause that you know ... I wouldn't want my husband to see me like that, it breaks his heart the way I am as it is. He can't deal with it a lot and I can't deal with it and we look at what we used to do together and we have a really hard time.'*

*'I can't really talk to anyone because I don't want to make my family upset ... I try to think of the good things and it's hard. But most of the time I don't do too bad.'*

*'My family doctor does what he can. He's a good GP. I get along well with him and he takes me for who I am. He listens to me and my problems and he tries to find out who does what or how we can do it ... I wouldn't have him otherwise because that's the last thing you need is to have a doctor you have to fight with. But you know bottom line, GP's haven't a clue the poor fellas and he's admitted it to me. Even top neurosurgeons have admitted it to me, they don't know, they really don't know.'*

*'I went for this direct funding interview ... and I left there in tears. The interviewers are supposed to be peers. The guy was in a chair. He made me justify why I can't make my bed, why I need to have a made bed. I had to justify my disability, even my weight. I had to justify everything. And then I find out later he has a wife that's able-bodied and does a lot of that stuff for him.'*

The women commonly described dealing with negative emotions that they attributed primarily to long-term stress. Sources of stress include day-to-day

life with a disability, financial problems, separation and divorce, legal battles with insurers sometimes lasting up to 10 years, and having to fight with a system that seems resistant to adapting to their changing needs. Many of the women describe more 'down' days with age, increased anxiety, marked absent-mindedness, tearfulness, and disappointment with themselves. The majority feel the trauma of the injury lingers many years – and possibly longer than anticipated at the time of settlement. They feel they are constantly adjusting to the injury and that their emotions are very close to the surface. The age related changes exacerbate the need for continued adjustment.

*'I just break into tears at the drop of a hat now. Emotionally I'm on the edge of tears every time you look at me.'*

*'I get very, very angry now. Really angry and I never used to be like that. I think it's part of being overwhelmed by things and I think I just have to breathe deep and I have techniques I do when I get like this. I'm very short-tempered now.'*

*'I'm not depressed, but I just have more down days now ... really down days.'*

*'People always ask me if you ever adjust. You would never choose to live a life with a spinal cord injury given choices. But since you don't you cope. I find it's an adjustment every time you make a major change in your life. As a disabled student I coped. Then there was another readjustment when I went into the workforce. When I got married and had a child there was more adjustment. Now it's adjusting to aging. So it's always a process of adjustment probably for most people that's life isn't it? But adjusting to trauma that's something in addition to keep coping with.'*

The women frequently described with age they have developed a profound sense of inner strength, self-acceptance, and re-evaluation of priorities. Those who were injured late in life saw this as a good thing in they are stronger and have already developed coping strategies. Some indicated they feel the injury/aging matrix has pushed them into self-exploration and development. They feel more spiritual and self-reflective, have learned how to function in a wheelchair, to pace themselves and are able to accept some of the limitations that come with the disability. They describe feeling bolder and more assertive and comfortable putting themselves first. They feel a preciousness of time and want to spend time on what they value. At the same time they indicate they feel less afraid now of growing older and dying.

*'Now that I'm older I understand myself better, my limitations, what I can focus on and what I can do better. I guess with aging comes a certain amount of*

*self-analysis. You can apply that to how you cope with your body and its limitations. You recognize what you can and can't do – what the links are ... When I'm like this I have to be careful about that and so on. That's something you learn with age.'*

The women sense that they are aging prematurely, and that while this has disadvantages associated with pain, loss of function and mobility, and increased independence and fear, they can identify some good things as well. They pointed out that when you get older with SCI, the worst is over. They feel that because they have already faced their mortality, they are not as afraid of dying. The losses have been sustained and they are already used to living with a disability. Whereas the women see many in the general population who never come to terms with disability and aging, as SCI survivors, they have been forced to do so. The women also feel advantaged in dealing with aging in that they have adjusted to reductions in the work role, are used to functioning with a disability and taking care of themselves, and have already had to learn to pace themselves and use their available energy wisely.

*'I guess before the accident I had some fear of dying and I don't think I have it nearly as much as I did before, because I was almost dead anyway.'*

#### *Aging related worries and concerns*

There were four main themes of worries and concerns related to aging. These are listed in Table 2.

By far the most predominant worry was fear of increased health problems and physical deterioration. The women fear increasing health problems, because such problems pose a threat to their independence. They fear becoming an increased burden, but also simply fear increased pain and discomfort and not being able to cope with it. The women feel at the limits of their capacity coping with the disability now, and any further declines would push them beyond the point of being able to manage.

*'I'm an artist. And I wake up in the mornings and have no feeling in my hands and I think, oh god. It just terrifies me that I would lose my ability to paint. I live alone and if I can't paint I'd be stuck sitting here with my thoughts all day long.'*

*'I think it's not so much the aging process which is inevitable for all, but it's the sort of compounding of these other health issues I've talked about; the bladder, the bowel, the osteoporosis, the things that disability imposes rather than getting wrinkly and maybe getting senile, it's the other aspects of spinal cord injury and knowing they will be compounded.'*

*Fear of increased dependency and isolation* This was common, particularly the fear of having to leave their

own home and 'be placed' in a nursing home. They are also concerned that they will not be able to afford a nursing home that understands their unique needs. The women stated that unlike the majority general population, they have experience with long stays in hospital and know how awful it can be. At the same time they worry about becoming an increased burden to their family. They expressed a profound sense of vulnerability and uncertainty about the future.

*'The cutbacks just terrify me. As I get older I'm afraid I'll get stuck in one of these lovely old ... crappy old homes sitting in a diaper messing myself and they won't be able to do bowel routines.'*

*'When I look around I'm scared. I worked with seniors for a lot of years and the ones that are very lonely because they have no family, no kids; it's not a very great future out there by yourself. You've got to start preparing for it when you are 30 or 35 because who's going to look after you? It's tough isn't it?'*

**Financial worries** These were significant, particularly for those without paid employment. Those on government support programs state that they will be terminated if they accrue any retirement savings. The women indicate that they already have trouble managing the extra expenses associated with living with a disability (equipment, transportation, attendant and housekeeping services, inability to shop for bargains because of accessibility and time constraints). They wonder how they will ever manage when their abilities and needs change with aging and they have even greater equipment and care expenses. They are very aware of the current economic cutbacks, wonder what is around the corner and fear they will be left to fend for themselves, without social services. The women worry that their insurance settlements and government support were calculated based on their health and function in middle adulthood. As they age and need more help and equipment, they wonder if funders will understand and whether renegotiation will be possible. Some have already discovered that they cannot obtain funding to cover their escalating costs.

*'You can't get out to the sales, or get stuff easily you know, so your costs are always higher for everything'*

*'I know I'll need more money for things like attendant help and equipment, but all you're allowed in liquid assets ... that includes anything you own ... is \$3000 to \$4000. That's it. So how can I save for the future? It's so frustrating and frightening. It's the financial aspects of aging. What are you going to do? You are at their mercy.'*

*'Being in the chair is the easy part of spinal cord injury. I've got to the point where I think walking is over-rated. But being old and poor and in a chair ... forget it ... bring on the bullet'*

The women with school age children frequently expressed strong feelings of fear and anguish that their declining function and health will prevent them from continuing to mother and 'be there' as a proper parent for their children. At worst they genuinely feared dying young and abandoning their children.

*'I worry that as I deteriorate I might be taken away from my children. I might not be able to be with them or selfishly to experience some of the things I would have with them ... maybe even as a grandmother ... I know my disability is shortening my life'*

#### *Strategies and resources*

The strategies and resources that the women currently use and view as instrumental in their coping with age related changes are listed in order of importance in Table 2.

The women believed strongly that their own attitude and behaviour was their most important resource for coping with aging and disability and being able to face what they fear lies ahead. They think it helps a great deal to achieve an attitude of acceptance, to learn to adjust to ongoing challenges, take one day at a time, and to recognize that they may have fewer choices but they are not powerless. They indicated that an attitude of determination – being assertive and feisty – is empowering. They value the insight and self-knowledge they are gaining with age. Maintaining a sense of hope is viewed as crucial; hope for a cure and hope that life would turn out well. They achieve this through various activities including pursuing a goal or project that energizes them, staying active doing things they enjoy, engaging in activities that give them a sense of being able to contribute and be useful. One participant stated she copes by 'staying close to the things I love'. The majority highly value the feelings of power and well-being they derive from physical exercise. Some find it empowering to deny their limitations by engaging in challenging high risk activities such as horseback riding, skiing, going out alone and working. They spoke of the power of maintaining a sense of humour and a positive outlook: 'You are only as old as you feel.'

*'I don't think the spinal cord injury has been a negative thing all the way around. There's been some positive things in my life after the spinal cord injury.'*

*'You may have coped in different ways when you were able-bodied and you have more limited numbers of ways to cope when you have a disability – fewer choices. It doesn't mean you don't have choices. For me it doesn't mean you have to feel powerless, but yes, there are fewer choices.'*

*'I try to rise above the negatives and feel powerful and part of life and tell myself I can give to others and if I help one person along the way then our lives are not useless, or worthless.'*

*Informal supports* These were identified as especially critical in the women's coping and adapting to aging with a disability. Spouse and family were most frequently mentioned. In some instances spouses were very supportive and the women feel they can depend on them with confidence. Those without spousal and family support expressed a longing for these things. The women are aware of the extra stresses their disability places on their spouse. They spoke of the important and frequent additional support provided by friends, extended family, neighbours, community groups and the Canadian Paraplegic Association. Those with children indicated that while they were demanding, they keep the women active and feeling young. They indicated that relationships with friends and peers are extremely important – as important as therapists or counselors. It is with friends and peers they can talk and share experiences, resources and challenges.

*'Yes, he (husband) knows how to change the catheter, he had to learn that because if something happened and I get plugged up'*

*'When I go out with my husband I don't even think twice about access and neither does he because he's used to taking me up and down stairs'*

*Formal supports and methods of dealing with them* These were identified as important strategies for coping with aging. Taking steps to be in charge and keep control of their own health, health care procedures, routines and attendant care were seen as crucial. The women indicated that they utilize complementary medicine (acupuncture, herbs, massage, marijuana). This is partly out of frustration with poor results from interventions such as traditional pain remedies. They value an holistic approach and incorporation of their emotions in achieving health. The women indicated that they value the personal relationships and continuity that develops with formal caregivers and service providers (physicians, attendants, homemakers) over the years and see these as important contributors to their health and well-being. They feel understood and validated when their physician actually listens to them and their concerns. This reduces their fear of what is ahead and whether they will have support and understanding and be able to cope with aging.

*'I remember my roommate was a quadriplegic 17 year-old girl who was thrown in the pool and that's her life gone at 17 years of age. She was such a nice girl and she was so quiet, she was so quiet, she wouldn't ask, you know, her nose would be itching and she wouldn't ask anybody, and I guess to this day I see her in my mind and wonder how many thousands of others are out there that don't speak up, and that don't ask. I guess the bottom line is I'm saying nicely that you've gotta be heard. Don't sit*

*back and wait for OT's or doctors to come up to you ... you have to let them know what you want and when you want it and how. You need to put your questions up front and don't be afraid to ask stuff and be heard. Because otherwise things happen to you, you slip through the cracks and then you get into real messes that are hard to get out of.'*

*'After dealing with every single solitary doctor and everything that goes along with spinal cord injury, it's made me a different person than before the accident. I'm much bolder, I'm more outspoken, I'm heard now, I don't sit back and be polite or shy or blush at things. Because it's the only way you can deal with this.'*

*Additional resources needed to achieve successful aging* Table 2 lists the resources identified by the women in order of importance.

*Improved assistive device technology and environmental accessibility* These were most frequently identified as needed resources for successful aging. The women also mentioned needing improvements in assistive devices including funding assistance for purchase of power wheelchairs. Even though power chairs are hard to accept, the women acknowledged that they do vastly improve function and independence. The women indicated there is a need for more comfortable bras designed for women with SCI due to sensitivity of the spine combined with larger breasts that they find come from weight gain and aging. They also indicate there is a need for design and availability of attractive practical clothes for women in mid-life and older who use wheelchairs. The availability of an accessible van vastly improves quality of life, freedom and spontaneity but costs are prohibitive. Most could not afford a computer, but indicated that especially as they age and are getting out less, it is an ideal way to stay in touch with the world, particularly for the women living rurally. They discussed the inadequacies of environmental accessibility at length. There was consensus that while there have been improvements, the environment still limits quality of life, basic tasks, socializing, housing choices, shopping, travel and access to hospitals and doctor's offices. These barriers are magnified as the women age and are more limited physically.

*'Oh, if I could get my car on the road, that would oh, are you kidding? I could take my dog down to the park, it would be freedom that says, 'Wow, look I'm alive! I'm out, I'm doing, I'm actually part of life and not just sitting around waiting for WheelTrans to take me here and there.'*

*'Everybody needs the power chair and a bit of a manual back-up chair, you have to have them both, and a lifting device, that's a necessity. And a computer is an essential'*

*'I live in a small village of 20 000 and it's poor of course. I can get into the grocery and drug store but most of the smaller businesses on the main drag are in older buildings and it's a step up so I don't go out in the daytime anymore. I have to wait til my husband comes home from work to help me now.'*

*The importance of flexible attendant care and household help* These were identified as paramount. The women indicated that well-trained attendants who are knowledgeable about SCI can play a significant role in averting medical problems. The women are afraid as a result of the trend in cutbacks. They know their needs are increasing with age and there may be need for an attendant where there was none, or an increase in attendant time. They indicate that there used to be a philosophy that attendants were to help complete basic tasks and thus free the person with a disability's energy up for their more fulfilling activities. But the women report that this is changing due to cutbacks. They find that household tasks are becoming increasingly exhausting and they need help but can't afford it and don't know how to get it.

The women expressed anger and frustration that the assessors for entitlement to the government direct funding of in home help, while persons with a disability, were frequently men. They stated the male assessors were often judgmental, discriminatory and dismissive of the work entailed in the women's roles in the household and so the women did not get the help they feel they need. They think it would help to hire more women, and to educate all assessors around attitudes to paid versus non-paid work and the value of both to families and society.

The women strongly emphasized their need for more peer and psychological support. They spoke with much bitterness about the neglect of their psychosocial and emotional adjustment needs during rehabilitation. They indicate that at least then they had peers in the institution to talk to and exchange information with. Some of these peers served as role models. Now that they have returned to the community however, many are far from cities and rehabilitation centers, and they feel they are facing life as a woman with a spinal cord injury and aging alone. They feel many of their needs could be met through peer support, as opposed to expensive professional visits, but they are isolated and feel they have no way to meet and connect with peers.

*'(During rehabilitation) I always felt strongly everyone should have had an hour minimally of psychotherapy, but there was nothing. I'm a psychotherapist. Patients tried to pin me down in the hall but I didn't feel comfortable about that as that wasn't why I was there.'*

*'It would have been good if there had been a woman on staff who was a clinically trained counselor with some experience in this field and who would make*

*herself available or lead groups on a weekly basis on a variety of topics.'*

*'And getting to talk to people that have maybe not had the same injury as you but are going through the same things or are in your age group. I find this is remarkable. It really, really helps me.'*

*'I've been in a chair for 22 years and I know there are women around who have been in it for 30 and 40 years. I'd just like to be able to talk to them about what has happened to them over the years.'*

The women indicated that they require improved financial resources to cope with aging superimposed on their disability. They are currently going without basic supplies and services and not participating in valued activities and exercise due to lack of funds. They view life with a disability as more expensive and see it only getting worse as they age and their needs increase. They feel anxious and fear poverty. They feel powerless to save and prepare financially for aging since most income and disability support programs have built in disincentives against even part-time employment income or savings. They need changes in policies that will encourage and permit rather than penalize saving and part-time employment for persons with disabilities.

*'Money would make things so much easier.'*

The women derive tremendous security and reassurance knowing there is active research in spinal cord injury. Many stated that they still hold hope for a cure and advancements that will allow them to walk again. They also hope for research leading to pain medications that do not make them drowsy and upset their bowel routines. They want more information specifically tailored to women and made available to both themselves and health care professionals. Topics of importance included SCI and sexuality, health risks, aging and SCI and what to expect and how to cope with the long term.

*'There's not a lot about women. You look at the resources. I've been looking up about menopause. There's nothing out there written about it. There's nothing out there written about spinal cord injury and menopause.'*

*'It's difficult to get information about spinal cord injury and aging. We haven't had spinal cord people last as long before. This is a bit of a new era. Sometimes you'd like to be able to get some facts to alleviate your concerns, particularly if they are inaccurate. It would be neat if there was an information site or network where you can sit down and get information beyond the specifics and changes for us as we age so we're not wandering off to some gloom and doom area that doesn't exist'*

*Recreation opportunities* For this group these are presently problematic in terms of availability, accessibility, and cost. This issue came up repeatedly in the interviews and focus groups, both for urban- and rural-dwelling women. They indicated that they derive tremendous health, emotional and social benefits from the opportunity to engage in physical exercise activities outside the home, and see this as important to maintain health and function into later life. They need improved access to recreational facilities in order to maintain strength and fitness, avoid overweight and associated health risks, and to socialize.

*'I'm disappointed that tax dollars that I pay don't go into making the community centers more accommodating for people in wheelchairs. They told me there is no room for me to do my weights at the local gym'*

## Discussion

In this study, the women reported that with age they are feeling less financially secure, are experiencing more symptoms and physical deterioration, fatigue and are decreasing their activity levels. These findings are consistent with both our examination of women aging with lifelong disabilities other than spinal cord injury and men aging with spinal cord injury.<sup>1,2</sup> In all instances the results suggest a premature (both physical and emotional/psychological) aging in persons with disabilities, requiring increased personal and household support and more assistive devices to enable continued social participation. The women with spinal cord injury are similar to other disability groups in their expressions of fear and concern about aging, while simultaneously demonstrating tremendous emotional strength and pragmatism.<sup>1-3,11,66,67</sup> What is unique about the women with spinal cord injury in this study are their profound feelings of isolation and perceptions of being forgotten and overlooked by health care and rehabilitation professionals and the social service system.

It seems important to communicate the extent of the anger and frustration expressed by the women during many of the discussions in the interviews and focus groups. These emotions were generally directed toward two groups. Firstly, the women feel that health care professionals have frequently ignored them and not made an effort to understand the unique issues arising from being a woman with a spinal cord injury. This is particularly true for the psychological and sexual aspects of the disability. If addressed by clinicians at all, the women reported these issues were viewed as static. They received 'one shot' attention, rather than dynamic and changing attention as the women mature and pass through the stages of adulthood. Secondly, the women feel that those who control service provision such as insurers and government agencies obstruct the women's efforts to adapt, modify and regain control of their lives and participate in the community in a meaningful way. Instead, the women

hope for a collaborative partnership relationship with these individuals.

The women's anger is an important cue and opportunity for persons working with this population. The psychological literature tells us that anger is usually in fact an expression of fear or a response to a perceived threat.<sup>68</sup> Based on longitudinal studies of adjustment to SCI we know that there is significant ongoing psychological adjustment and that psychological distress does not diminish significantly over time.<sup>77</sup> Rather than reacting defensively in response to the women's anger, health care, rehabilitation and related professionals need understand that the women's anger and frustration often originates from fear. Many fears were clearly expressed in this study including fear of being able to cope with aging, of losing personal control, of losing cherished relationships and the ability to participate in valued activities; fear of poverty; fear of having their concerns dismissed by providers, and fear that the system will not respond to support their changing needs as they grow older. Understanding the women's anger as outward expressions of fear paves the way for relevant, effective and collaborative problem-solving.

Effective problem-solving and solutions for many of the aging related problems identified by these women with spinal cord injury will include strategies that facilitate their feelings of personal control. These may be achieved through access to information, listening to and acknowledging their fears and concerns and – where possible – addressing them directly, facilitating peer support, and enabling them to gain a wider repertoire of skills for coping with stress. These coping strategies may include psychological strategies such as self-advocacy, assertiveness, anticipating and coping with change. Physical strategies include strengthening and conditioning, joint protection, pain management, bowel and bladder management, more information and support around sexuality issues and options. It is also vital to facilitate continued engagement in meaningful and rewarding life roles.

While not directly related to aging, the participants were virtually unanimous in the view that their initial rehabilitation focused on their physical impairments and stressed physical independence but ignored both personal and family emotional adjustment. While the short-term and emotionally tumultuous nature of the acute inpatient rehabilitation period may blur recall of the regular counseling and support groups that were likely held during this period, it seems to have been a failed opportunity to facilitate long term emotional adjustment and set up peer support programs (formal or informal) for post-discharge. The women wisely point out that without support and coping strategies to draw on after discharge, their suffering is magnified and both they and the family unit are at far greater risk both in terms of emotional and physical health. Clearly – even during initial rehabilitation – personal, couple and family counseling is important. So too are inpatient support groups and formalization

of peer connections that will continue post-discharge. Life with a disability is a long term and unpredictable endeavor. There needs to be early development of skills, strategies, tools and resources to enable to women to adapt to the changes associated with aging.

The women feel isolated and crave information that will assist them to take more control of and responsibility for their own health. This was particularly evident in those who live outside major centers. Their primary health care contact was most often a family doctor whose knowledge of spinal cord injury was limited to experiences with that one patient. The women want to delay the effects of aging by maintaining their health with behaviours such as exercise, a healthy diet, and minimizing infections and medication use. However, they experience obstacles that include access to fitness facilities, lack of money, and tremendous difficulty accessing information and services specific to women with SCI. There has been only limited work published on the health promotion practices of women with disabilities suggesting that they are limited relative to women in the general population.<sup>69-71</sup> The reasons are not clear, but for the women in this study they appear to include lack of information, funds to participate and accessibility. As Table 1 reveals, this participant group is generally highly educated. During focus groups, the women's need to seek information, ask questions of each other, share and exchange experiences and information was overwhelming. Indeed, the focus group experience seemed so useful to them that most asked to exchange contact information so that they can stay in touch as peer supports. Women are known to be more relational than men and to develop and value broader systems of social emotional relationships which they use to derive support and draw on during times of stress.<sup>72</sup> The women in this study in particular seem to need more opportunity to be able to connect with, share and exchange with peers on an ongoing basis.

Potential solutions to the women's perceived needs for more information about living with a spinal cord injury, health and health promotion, and improved social support include:

- peer support groups that meet regularly by telephone so that rural and high level injury women could be included,
- tele-health programs for the women that include staff such as nurse practitioners with expertise and information specific to women with spinal cord injury,
- tele-consult programs for family doctors that give fast-access consultation with physiatrists/specialists in spinal cord rehabilitation. Better still would be consultation access with that patient's particular physiatrist in a major center.

A very clear message from women was that it is not so much solutions and answers that they want; they

know in some instances this is unrealistic. But they need to feel that there is somewhere they can turn where they can ask questions, find out about new resources, assure themselves they have current information about the management and coping with their injury, express their concerns, and generally know they will be heard and supported.

The participants had many primary health related concerns that centred around gynecological issues, bowel and bladder, upper limb musculo-skeletal pain and difficulty with weight gain. The small body of health related research on women with disabilities has focussed on their unmet primary health care needs, the prevalence of secondary conditions, and sexual and reproductive health. The prevalence of secondary health conditions in women with disabilities is significant including pain, functional losses secondary to life in a wheelchair, age-related changes, chronic urogenital problems, hormonal changes, weight gain secondary to reduced mobility, osteoporosis, poor dental health, heart disease, depression and osteoarthritis at younger ages than able-bodied controls.<sup>69,71,73-75</sup> The women in this study expressed feelings of powerlessness to cope with their health, threats of physical decline and a profound fear of the future. Some of this fear stemmed from their perception that the health care system is presently not able to meet their needs. Qualitative examinations of the meaning of health and disability for women with disabilities revealed them to spend tremendous energy struggling and coping with negative disability stereotypes in society and negotiating the barriers and intolerant attitudes they encountered daily.<sup>76</sup> Other concerns reported, including in our previous study of women aging with longterm disabilities, include sexual and reproductive issues, attitudinal barriers and a health care system that is unaware and poorly equipped to deal with their needs.<sup>1,69-71,73-75</sup>

In conclusion, our research suggests that women with spinal cord injury have unique concerns and experiences with life with a disability and facing aging. Our findings send a clear message about their needs for the following resources:

- peer support particularly for women who return from rehabilitation to live outside of major centres that lack population with spinal cord injury, facilities and services and health care professionals with disability-related expertise;
- early and ongoing support and intervention for psychological, relationship and sexual issues for both the women who have been injured and their spouses/partners;
- clinical attention, education, research and development around gynaecological/reproductive/sexual and urogenital issues unique to women with SCI; and
- as their ability to perform tasks declines with age, there is a need for a social and economic safety net

that is accessible, flexible and responsive in its willingness to enable them to adapt to their changing needs.

### Note added in proof

The authors certify that all applicable institutional and governmental regulations covering the ethical use of human volunteers were followed during the course of this research.

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