

Original Article

Perceptions of issues associated with the maintenance and improvement of long-term health in people with SCI

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Study design: Qualitative design using focus groups.

Objective: To explore the perceptions of people with SCI and their caregivers about information needs and service delivery options that may assist them to maintain or improve their long-term health.

Setting: Province wide project in Alberta, Canada.

Methods: Eight focus groups were conducted; five with community dwelling people with SCI and three with unpaid caregivers (family and friends). Content analysis was used to identify categories and themes arising from the data.

Results: The findings from the study are broader than the original objective to explore information needs and service delivery options to promote long-term health. The participants more globally discussed factors that contribute to or provide barriers to their long-term health. Those factors are captured in five categories, including readiness, information pathways, community health care, health promotion, and contextual factors. A framework that illustrates the relationships between categories was constructed.

Conclusion: The framework identifies areas to target in programmes designed to reduce or prevent secondary conditions in people with SCI.

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Introduction

Secondary conditions are ‘preventable medical, physical, cognitive, emotional, or psychosocial complications of physical impairment’.¹ An individual with spinal cord injury (SCI) is at increased risk for several common conditions like diabetes and heart disease over their lifetime, and very often at younger ages than their non-disabled counterparts.² They are also at risk for secondary conditions such as bladder infections and pressure sores, conditions that will not affect their non-disabled peers and result in increased utilization of the health care system by people with SCI.³ Management of secondary conditions in people with SCI is an ongoing process that depends on consistency, vigilance, up to date information, and life long learning skills.⁴ Patient education during the rehabilitation phase of SCI (ie the

initial rehabilitative stay following acute management) is a component of preventative rehabilitation and is designed to educate patients about secondary conditions and how to prevent them in the long term.⁴

The timing of education about prevention of secondary conditions during that initial phase of rehabilitation is challenging. It may be difficult for someone with a new SCI to recognize the importance of the prevention of secondary conditions when they are coping with the overwhelming physical and psychosocial changes associated with a SCI.⁴ The dilemma is that during this time the person with SCI has the most access to experts knowledgeable about SCI.⁴ To address these challenges, inpatient rehabilitation programmes may be designed to help individuals cope with and accept information more readily, or provide strategies to help people utilize information after they are discharged and perhaps more ready to receive information.⁴ Alternately, education and information about secondary conditions could be provided to people with SCI after they have returned to

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the community. The last alternative is supported by recent research which emphasizes that patient education about health and healthy living for people with SCI should not end after the initial rehabilitation phase.^{5,6}

Designing and evaluating community-based strategies to promote the health of people with physical disabilities, including education, are of increasing importance as people with physical disabilities live with their disability for many years.⁷ Theories of health promotion and health behavior change are specifically applicable to community based strategies. Stuijbergen *et al*⁸ present an explanatory model of health promotion and quality of life developed primarily with people with multiple sclerosis but more recently applied to people with post polio syndrome.⁹ The model describes antecedent factors that impact health promoting behaviours and ultimately quality of life. Antecedent factors include the severity of the illness, barriers to change in health behaviour (such as architectural barriers), resources, and self efficacy. In all, 58% of the variance in health promoting behaviours was explained by knowledge of antecedent factors.⁹ The transtheoretical model of health behaviour change¹⁰ describes five stages of behaviour change including: (1) precontemplation; (2) contemplation; (3) preparation; (4) action; and (5) maintenance¹¹ and has recently been applied in populations with physical disability.^{12,13} Recognition of the stage of change a person is in with regard to a certain health behaviour, allows the intervention to be tailored to the individual's needs.¹⁴

This study was part of a 2-year collaborative province-wide project of which the main objective was to develop standardized education materials for consumers (people with SCI), caregivers, and health care providers, with the goal of maintaining or improving the long-term health of people with SCI. The project was developed partly to address a recognized need to provide appropriate information along the continuum of care, from acute care to the community.

The objective of this first phase of the project, described herein, was to explore the perceptions of persons with SCI and their caregivers about information needs and service delivery options that may assist them to maintain or improve their long-term health.

Methods

Research design

This qualitative investigation used focus groups to address the objective of the study. Focus groups are essentially group interviews that assemble people who have specific knowledge or experience regarding the topic of interest.¹⁵ The success of focus groups depend on comfortable environments that are permissive and nonjudgmental¹⁶ and one of the advantages of focus groups, over individual interviews, is the group dynamics that can be achieved that encourage discussion and produce and explore ideas and topics.¹⁷ In the present study, it was useful to explore the topic of

information needs in a group as the participants were able to cue each other about patient education in the rehabilitation centre (which was at least 1 year in the past), and together explore information needs about the prevention of secondary conditions, now that they were living in the community. The discussions as well as the interactions¹⁸ that result from focus group deliberations comprise the qualitative data obtained.

Participants

Canadian Paraplegic Association (CPA) staff in three different urban centres in Alberta recruited participants from their membership. Purposive sampling was used by the CPA staff, in consultation with researchers, to identify CPA members to participate in the focus groups. Participants were selected if the CPA staff (who knew all the potential participants) believed that they could provide their perceptions about information needs and delivery options to promote long term health (ie first and foremost, participants were selected for their perceived ability to contribute to the purpose of the study). We also asked CPA recruiters to identify participants with varying experience living with SCI. Specifically, we wanted to interview three groups of people; (1) people with SCI of <5 years duration; (2) people with SCI more than 5 years duration; and (3) caregivers (family members or close friends, not paid caregivers) of people with SCI. Other than duration of injury there were no other criteria with respect to demographic characteristics of potential participants. Many of the caregivers who participated in the focus groups were recruited in concert with their SCI counterpart (ie parents came to a caregiver focus group one night, the next night the individual with SCI [their son] attended the focus group for individuals with SCI).

Although we attempted to divide the SCI participant focus groups by duration of injury, it was not logistically possible, thus participant characteristics are presented for all participants. There were a total of 23 males and 12 females with SCI (age 39.0 ± 12.1 years; duration of injury 8.5 ± 7.0 years) who participated in the focus groups. Nineteen participants had a cervical level injury resulting in tetraplegia and 16 participants had thoracic or lumbar level injuries resulting in paraplegia. All but two of the participants with SCI had functionally complete injuries.

Caregivers (23) participated in the focus groups with the majority being parents (three sets of parents, one mother) or spouses (three male spouses, five female spouses). Other relatives included a brother, sister, daughter, aunt, and a grandmother. In addition three caregivers identified themselves as friends (two females, one male). Of the caregivers, all except two of the friends and two sets of parents, lived in the same house/apartment with the individual with SCI. Approximately two thirds of the participants (both caregivers and people with SCI) lived in urban centres.

Procedures

Prior to the initiation of the study, approval from the Health Research Ethics Board (Health Panel) at the

University of Alberta was obtained. Eight focus groups were conducted in three different urban centres throughout Alberta, in the offices of the CPA. There were five focus groups that included individuals with SCI and three focus groups with caregivers. SCI and caregiver groups were interviewed separately to facilitate examination of differences and similarities with respect to information needs. One of the authors [PJM] and a research assistant conducted each of the eight focus groups. Prior to the beginning of each focus group, the project purpose and the focus group structure were reviewed stressing the importance of respecting the opinions of all members of the group. The facilitators emphasized that a variety of ideas were being sought and that consensus was not the goal of the focus group.¹⁵ Participants were reminded that absolute confidentiality was not possible in a focus group setting but that names would not be used on transcripts, and results would be reported as a summary of all focus groups. Participants were invited to ask questions regarding the process after which they signed the informed consent.

The focus group session was divided into two parts: a written questionnaire and an open-ended discussion. The questionnaire took 5–10 min to complete and was designed as a warm-up exercise for participants, to get them thinking about information needs for long-term health promotion. The questionnaire was developed based on the topics of the SCI education programme and previous research¹⁹ and was intended to introduce potential information topics, in the broad areas of physical health and quality of life, and direct attention to the identification of information gaps (Table 1). The participants were asked to think about how important a topic was and how often they sought out information on that topic in the past 2 years. The results of the questionnaire were not analysed as it was only intended as a starting point for the focus group discussions. We considered the possibility that the topics on this questionnaire may impact and constrain the focus group discussions. However, we felt this starting point was necessary to help focus and at times reorient the discussions to the purposes of the study. The facilitators frequently asked about gaps in information to ensure that the participants did not restrict themselves only to discussions of the topics on the questionnaire.

After completion of the questionnaire, the focus group discussion commenced. A semistructured interview guide (Table 2) was used to explain, clarify, generate examples and explore information needs and methods for access and delivery of information. The researchers facilitated the discussion, observed and took field notes. Each session was tape-recorded and transcribed verbatim for analysis.

Data analysis

Conventional content analysis²⁰ was used to identify and code themes or patterns arising from the data of the group discussion. Each of the authors read the transcripts independently and used open coding to break down the data into units of information²¹ and to code those units of information. Together the authors

Table 1 List of education topics in questionnaire (Sections A and B apply to both persons with SCI and their caregivers, Section C applies only to caregivers)

<i>A. Physical health</i>	
a.	Anatomy changes
b.	Bladder management
c.	Blood pressure (including autonomic dysreflexia)
d.	Bowel management
e.	Circulation
f.	Medications
g.	Nerves, muscles, & bones
h.	Pain management
i.	Respiratory care
j.	Range of motion
k.	Skin care
<i>B. Quality of life of the individual with SCI</i>	
a.	Accessing community resources
b.	Activities of daily living
c.	Assistive devices
d.	Home modifications
e.	Instrumental activities of daily living
f.	Psychosocial adjustment
g.	Sexual health
<i>C. Adjusting as a caregiver</i>	
a.	Developing advocacy skills
b.	Coping with changes to family relationships and roles
c.	Minimizing stress and avoiding burnout
d.	Discovering community resources and how to access them

reviewed the transcripts line by line to discuss and agree on the coded units of information. The coded units were then grouped into categories and the relationships between categories were determined.²⁰ Axial coding was used throughout the analytic process to identify sub-categories of information.²¹ The framework of the categories was then reviewed to identify common themes or recurring messages that emerged from the data.

To ensure trustworthiness of the data, member checks were completed with a subsample of participants. A brief summary of the findings from the study was prepared and mailed to eight participants of the focus groups. In subsequent phone follow-up, member check participants were asked if the findings made sense, were plausible and accurate. The member checks gave no cause for modifying the categories or the framework.

Results

Framework

A framework was constructed that represented the perspectives of the participants about the factors that impact the maintenance or improvement of their long-term health. The framework is conceptualized as a pyramid depicting the interrelationships between the categories and subcategories (Figure 1). At the base of the pyramid is *Readiness*, the central category and the foundation for all other aspects of the framework, which ultimately leads to the action category of *Health Promotion* at the apex of the pyramid. The transition from *Readiness* to *Health Promotion* is mediated by the

Table 2 Semi-structured interview guide

<i>People with SCI</i>	
Education topics	<ol style="list-style-type: none"> 1. Are the education topics listed ones you feel are important in assisting you to live a healthy life with a SCI? 2. Are there any education topics that were missed or irrelevant? 3. What do you value in a health care provider? (ie attitudes, timeliness, knowledge) or what's important to you when receiving health care. 4. Have you used the information booklets about SCI over the last year?
Delivery of information	<ol style="list-style-type: none"> 1. How do you find the answer to questions about health related problems that you have experienced? 2. If some of the information about healthy living with SCI was not delivered in the rehabilitation centre, how would you best get that information?
Timing of information	<ol style="list-style-type: none"> 1. What do you think is the best time for you to learn about topics related to healthy living with SCI? 2. Do you think that you and your support network (parents, spouses, and friends) were ready to learn about strategies to maintain health with SCI at the same time? 3. Discuss topics you think need to be discussed in the rehab centre and ones you think might have been left until later when you were home.

Note: Questions in caregiver focus groups were similar but phrased so they applied to family members of people with SCI.

categories in the middle section of the pyramid. When participants were at the stage (ie in a readiness state) where they were actively pondering ways to enact health promotion strategies, they were much more likely to seek out information (*Information Pathways*) or community resources (*Community Health Care*) related to health promotion. Once information or community resources were accessed, participants moved towards *Health Promotion* in which they were actively utilizing the information or community resources they identified for long-term health promotion. This reciprocal relationship between the category of *Health Promotion* and the central categories is indicated by the bidirectional arrows. *Contextual Factors*, both environmental and personal, was an underlying category that impacted all other categories. Although the context of the discussion may have differed, there were no differences in the information needs and or preferred delivery methods of education/information for caregivers *versus* people with SCI and the framework applies equally well to both groups.

Categories

Readiness Readiness for information was discussed frequently and has implications for each of the other

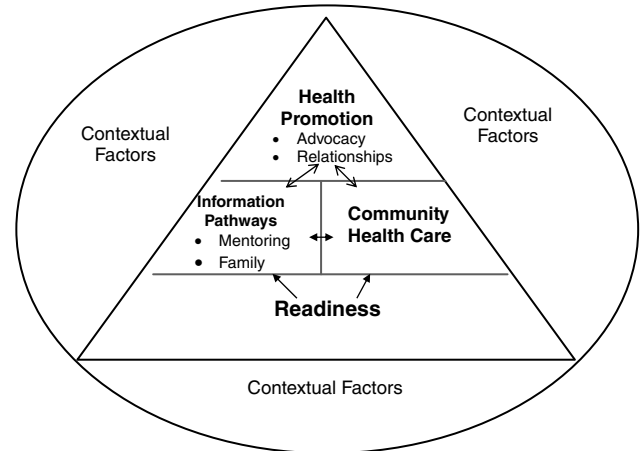


Figure 1 Factors contributing to the optimization of long-term health in people with SCI

categories in the optimization of long-term health for people with SCI. *Readiness* to learn or seek information relies on the individual's ability to recognize information needs as they apply to their own individual situation. The difficulty, particularly in the rehabilitation hospital, was recognizing what information was important, in the face of all that was happening. One caregiver stated, 'I just think ... after the accident you're in such shock and your whole life is just totally turned upside down that a lot doesn't sink in. And there's just so much to handle'. A participant with SCI commented on an education session that occurred in the hospital, 'Like, everything is not real for a long time... I just remember her [nurse] being there. I don't know what she even said. I don't have a clue'. Medical management such as medication use and acute healing from SCI affected readiness to learn; one person with SCI stated, 'So much morphine, I couldn't think'. Many participants talked about how readiness for information was an individual and unpredictable process that evolved from injury to the rehabilitation hospital to the community. That concept is reflected by the following statement from a person with SCI, 'and a lot of it for me, it was more important once I was out in the community and then I knew more what I needed'. Readiness was the foundation for the other categories on the path to life long health promotion.

Information pathways The category of Information Pathways represents the topics that our participants felt were important to learn about in order to maintain their long-term health. Information pathways include both information delivery and access methods. Clients with SCI frequently discussed the need for information about topics related to physical health, including skin care and muscle spasms, with the most prominent topics being bowel and bladder management. Despite stressing the need for information during inpatient rehabilitation, to prepare for a successful transition to home, participants also talked about the volume of information at times

being inappropriate. One person with SCI stated, 'Yeah. Yeah. I think the information that you get attending the rehabilitation centre is, in my opinion, far too much for a very short period to time'. A caregiver (in a separate focus group) concurred, 'and I agree wholeheartedly that information is given too much at once'. One person with SCI suggested, 'and so I think this education thing has to be spread out over a fairly long period of time'.

Participants also spoke of topics related to quality of life as represented by community and social reintegration. Desired information included information about equipment, relationships, vocation, sexuality, parenting and driving. Women in the groups noted that gender specific information related to relationships, sexuality and parenting was especially sought after once in the community, and not always easy to find. In addition, participants wanted to know more about the changes that may occur in the long term with spinal cord injury, and information that would give them hope for the future. As one person stated, 'because you need to know whether there is life after your injury. That you're not just going to be sitting at a table building puzzles and watching TV. There's more to it than that'.

Regardless of whether the desired information was related to physical, emotional or social health, participants discussed different information delivery and retrieval strategies and expressed individual preferences. They also considered the limitations of those strategies when deciding whether or not to use the information. For example, participants recognized the limitations of the Internet, as one person with SCI stated, 'the only problem with the internet is you gotta kind of understand because its overwhelming the amount of information out there... [the internet] may not be giving you accurate information'.

Mentoring and *Family* were subcategories of Information Pathways. Mentoring was discussed primarily as an information delivery strategy and participants sought both casual and formal mentoring relationships along the continuum of care. They also wanted a balance of information that highlighted both successful and challenging experiences. One participant with SCI was concerned in one instance that a visit from peers during rehabilitation addressed mainly positive aspects of their lives. He indicated that, 'I'd like to have seen them talk about the other side of it, too... Maybe a more clearer picture of everything.' Informal relationships with mentors, 'because you're all in a common situation' was important to both persons with SCI and caregivers particularly for information of practical experiences. The inclusion of *Family* in the education and information gathering process was regarded as important to prepare families about expected physical and emotional outcomes following SCI. It was felt that consistent involvement of family in the information loop could minimize adjustment difficulties. The importance of *Family* in processing and relaying information was particularly noted. One woman whose mother was a nurse stated, 'but then she [mom] was able to kind of tell it to me in a way that I could relate to it...'

Community health care The category of Community Health Care describes available community resources, and awareness and satisfaction with those resources. *Community Health Care* was recognized by our participants as an important factor contributing to the long term health of people with SCI. Resources included traditional medical professionals such as physicians, occupational and physical therapists, nurses, psychologists, and social workers as well as community health and fitness facilities and their staff. In addition many participants were aware of or had used the community health link system, a provincial 24 h telephone information system in which nurses assist callers in identifying their health problems and care plan (ie you need to go to the hospital now, or you can wait to visit a doctor tomorrow). The services of the Canadian Paraplegic Association were also recognized as an important resource for the maintenance of long-term health of people with SCI.

In spite of seemingly plentiful community resources, many participants stated that it was difficult finding out what community resources were out there. One person with SCI commented, 'how do you know about something you don't know about?' Participants recognized that appropriate community health care relies on awareness of community resources by both health care providers and clients. When participants were ready and actively seeking community health resources to help them promote their long-term health, they found it was frustrating to not know where to go.

Once participants did access community health care services, there was a general feeling that many community health care providers knew very little about SCI. This perceived lack of knowledge was seen to impact the health care providers' ability to provide effective care to people with SCI. One participant discussed his experiences receiving appropriate equipment after being discharged home, 'funding isn't the issue. It's finding someone who knows what they're doing to help you.' Many participants recounted occasions where they educated health care professionals about SCI. One participant with SCI talked about his family physician, who initially knew very little about treating a person with SCI. He stated, 'but you know what, he [family physician] makes up in effort, what he lacks in knowledge. So, I've stuck with him. We've learned together, I guess.' One caregiver (fiancée) also talked about their experience with health care professionals, '...and you're going to know more than they probably know, so don't be afraid to accept that fact, that you do know more than they do'.

Participants also recognized that information needs were ongoing and would change over the years. One person discussed how this need was important for community health providers to recognize and address. They stated they wanted to, 'talk to someone who's knowledgeable in the process of changes and some of the things that might be happening to them and what possibly is expected to happen to them more frequently'. One person with SCI commented, 'I think it's important

to realize that in the future that as changes start to occur you're going to have more questions, so where to go and who to contact in order to get information'. This last quote encompasses all of the foundational aspects of the framework leading to the final category of *Health Promotion (Readiness* – having more questions; *Community Health Care* – where to go, who to contact; *Information Pathways* – get information).

Health promotion The process of actively utilizing available information and actually accessing community resources to improve the long-term health of people with SCI falls into the *Health Promotion* category. *Health Promotion* is about actively taking responsibility for the maintenance and optimization of health. This category was the action category. It represented what people actually 'did' with the knowledge and information they had (or received), or community resources available and known to them. Health promotion activities discussed included monitoring skin, increasing activity, managing weight, regular preventative tests, and in general 'pay[ing] more attention to what your body's doing overall' or getting to know bodily functions better. Learning the signals of the body or 'what your body's telling you', and having confidence to act appropriately on those bodily signals was very important to health promotion.

Advocacy was one of the two subcategories under *Health Promotion*. *Advocacy* is about taking control to facilitate optimal care of emotional and physical health. Participants recognized that there were benefits to being proactive and advocating for oneself. Even though advocacy was important to health promotion as a whole, several of our participants struggled in advocating for their health within the health care system. Nevertheless, participants agreed that like it or not, they were the best people to advocate for themselves as they knew the most about their SCI and how it potentially affected their health. One participant with SCI stated, 'I think I've learned the hard way that unless I'm my own advocate, I sometimes don't get the care I need'.

The subcategory of *Relationships* highlighted that *Health Promotion* was also clearly about promoting emotional and social health in addition to physical health. Emotional and psychosocial support was very important to health promotion and represented what people with SCI or caregivers did to achieve the support they needed to maximize emotional and social health. A big part of maximizing emotional and social health depended on the quality of the *Relationships* our participants had. Participants discussed the importance of establishing and maintaining relationships post SCI but recognized that it required an emotional investment and commitment to understanding that was shared by both partners in the relationship. As one participant indicated 'it's an up and down battle all the time'. A caregiver (wife) talked about the stresses and challenges in their relationship, particularly in the early years, 'But I mean the loss that he suffered and me trying to be

super mom and super woman and super helper and not understanding anything about burnout and trying to make his life worth living and taking this all on before I realized boundaries and everything like that'.

Contextual factors As described in the International Classification of Functioning, Disability, and Health,²² *Contextual Factors* include both environmental and personal factors. Environmental factors include barriers in the everyday environment such as aspects related to physical structures as well as attitudinal barriers associated with interactions with other persons. The ICF term was applied to the framework based on the fit between the discussion of the participants and the description of Contextual Factors in the ICF model. Our participants discussed several barriers that had an impact on the process of accessing and utilizing information and community health services.

First and foremost, people discussed architectural barriers and even with improvements to the accessibility of buildings and facilities over the years, many participants felt that physical access continued to be a barrier to their health. They were unable to get up on examination tables, unable to access the equipment in fitness facilities, or in general had challenges in accessing their environment fully. In some cases, it was apparent that a modification to the environment was the primary intervention needed to reduce a barrier to community health services, and facilitate health promotion. A husband and wife described how they used creative solutions such as taking digital photos of a pressure sore to surmount the environmental challenge of access to the examination table. Availability and knowledge of appropriate equipment such as wheelchairs was another environmental factor frequently discussed. Several participants were frustrated with the process of acquiring an appropriate wheelchair (as well as other equipment) and discussed the negative impact that had on their ability to access the community.

The attitudes of others are also environmental factors and were discussed as potential barriers to the optimization of long-term health and integration into the community. One participant recounted his experiences going out in the community in a wheelchair, 'the first time I used a wheelchair it was just an absolute shock to actually see people... and to meet people and people actually looking at my wife yet talking to me'. Some participants felt that the attitudes of others affected their ability to achieve optimal health. One individual recounted 'I wanted to join Weight Watchers. Weight Watchers wouldn't take me because I couldn't weigh myself.' Another participant who had a musculoskeletal injury that she perceived was not adequately treated, was upset because of the apparent lack of understanding by the health care professional of the importance of her hands and arms, and how that affected her ability to be functionally independent. She said, 'Fix the people to their full capability. Don't take the attitude that it doesn't matter because they're in a wheelchair'.

Themes

In addition to the categories within the framework, there were two primary themes that emerged from the data: *Individualization* and *Collaboration*. These themes had applications in each of the categories. Participants recognized and discussed the challenges in designing an education programme that was responsive to differential states of readiness, different preferred modes of information delivery and varied community resources throughout the province, and various action plans around health promotion. One participant with SCI stated, 'But I think everybody is different in when they're ready to accept certain pieces of information'. Individualization emphasizes the need for multi-dimensional approaches to education and information delivery.

The second theme, *Collaboration*, recognized the importance of reciprocal relationships between people with SCI, their families and caregivers, and health care providers, policy developers, and community facilities. One participant discussed the role that they as a person with SCI had in working with others in society to promote their long-term health. They stated, 'And I think that we have to educate society continuously that we want to participate fully, OK, that we value ourselves as much as anybody else, and that we have the same rights to all those good things, preventative care, strategies, and so on'. The achievement of optimal long-term health outcomes for people with SCI is a shared responsibility.

Discussion and conclusion

Discussion

This qualitative study was designed to determine education/information needs related to the long-term promotion of health of community dwelling individuals with SCI and their caregivers. As the discussions in the focus groups evolved, the results of the study became broader than the determination of information needs in that they captured the factors (which included service delivery and contextual factors) the individuals with SCI and their caregivers perceived were important to their long term health. The framework developed can be used by people with SCI, caregivers, and potentially health care providers, to help to understand the path to life long health for people with spinal cord injury, and the factors that facilitate or provide a barrier to lifelong health.

Our framework is similar in some ways to Stuijbergen's explanatory model of health promotion and quality of life.⁹ Both recognize the negative effect of barriers (ie architectural) in health promotion. We describe community health care and its importance in health promotion whereas the explanatory model of health promotion and quality of life talks more broadly about resources including social support, environmental and tangible resources. Social support is also important to health promotion in our framework, but is captured

more in the subcategories of family and relationships. Readiness as a category is analogous in many ways to the precontemplation, contemplation, and preparation stages described in the transtheoretical model of health behaviour change.¹¹ In addition, the transtheoretical model describes helping relationships as one of the processes that may affect behaviour change, which is comparable to mentoring described in our model.¹⁰ It may be possible to apply the transtheoretical model of health behaviour change to prevention of secondary conditions in SCI, so that interventions can be tailored to a specific stage.²³ The focus on readiness in the transtheoretical model and our model emphasizes the importance of addressing that concept with people with SCI in order to gain the necessary knowledge and skills for lifelong prevention of secondary conditions.

Wolfe *et al*²⁴ suggest two strategies to address the challenge of readiness. The first is to provide programmes that 'help individuals cope with and accept information more readily'. Our participants felt that readiness was a very individual process, and even with programmes more specifically targeted to help facilitate readiness, it is likely that there are many persons with SCI who will simply not be ready to effectively take in information about the prevention of secondary conditions when they are still in the rehabilitation hospital. In our previous research, learning readiness was identified as an issue by SCI inpatients with respect to the education programme during rehabilitation.²⁵ Experiences of caregiver participants in accessing and relaying information also reflected differential states of readiness.

The second strategy presented by Wolfe *et al*²⁴ is to 'enable individuals to find and utilize information more effectively after discharge from the rehabilitation hospital'. This is likely a more viable strategy because we know that, 'patients seek answers to their questions at the time they formulate the questions'.²⁶ Many times those questions will arise after discharge from the rehabilitation centre. It may be feasible to use problem-based learning (PBL) as a teaching model for the SCI inpatient education curriculum because it is a model that encourages the participants to develop strategies and processes to answer their own questions.²⁷ It may also address one of the identified weaknesses of inpatient education which is that participants improve their knowledge but problem solving abilities remain limited.²⁵ PBL may address some of the challenges to readiness as well as the need for lifelong learning in this population.

A third strategy to consider in addressing the challenges of readiness is moving some of the delivery of patient education information about secondary conditions from the rehabilitation hospital to the community. Our participants talked frequently about the use of the Internet for information upon their return to the community. There are several good Internet sites that address health after spinal cord injury (for one example see www.carecure.org). Knowing which sites are good is a dilemma and it is helpful to have a baseline level of knowledge in order to be an educated consumer.

However, the importance of mentoring was so often emphasized by our participants, the Internet cannot be the only avenue of education/information available to people on their return to the community. In addition, older people with SCI do not utilize the internet as frequently as younger individuals⁴ and thus different modes of information delivery are needed. The significance of mentoring was emphasized during this study as it was noted that the focus groups became an informal mentoring group in some cases.

Information delivery using the principles of self management²⁸ is a strategy to consider for community based patient education for people with SCI. Self management focuses more on teaching problem solving skills, as opposed to traditional patient education which may focus more on information and technical skills.²⁹ The development or enhancement of self efficacy, or the confidence with which a person is able to carry out a task, is a central part of self management.²⁹ Self efficacy is also a concept central to the explanatory model of health promotion⁹ and is incorporated into transtheoretical model of behaviour change.³⁰ We know that self efficacy is an important predictor of health promoting behaviours in people with disabilities.³¹ Self management approaches also use peer leaders, which would address the importance of mentors identified in this study. Self management approaches have been used with patients with arthritis and diabetes,^{32,33} but to our knowledge, have not been used with people with SCI. Any approach to education, however, needs to focus on the topics of most importance to people with SCI.

Previous studies with people with SCI have discussed education primarily around topics related to the reduction of secondary conditions; and secondarily about topics related to community integration.^{34,35} We think patient education can be used to address topics related to community reintegration such as relationships, parenting, driving, vocation and others that may affect physical health but will particularly enhance emotional and social health. Our participants indicated a need for more information about topics related to community integration. It was clear that patient education needs for our participants evolved over time from those related to physical health to those related to community reintegration. Education needs that evolve over time demand innovative delivery of education, both in the hospital and in the community.³⁴

This study highlights contextual factors as factors to consider in long-term health promotion for people with SCI. Contextual factors are external to the person. They are factors over which the individual has little or no control but factors that can directly or indirectly impact emotional and physical health or the opportunity to optimize emotional or physical health. Previous studies have shown that good access to the environment outside a person's home was a predictor of life satisfaction.³⁶ Contextual factors affected all categories in the model, but primarily affected community health care and health promotion. Health care providers must recognize and address some of the accessibility and

attitudinal issues that remain in doctor's offices, preventative health care clinics, and exercise facilities. Improved accessibility in health care centres and fitness centres has implications for many populations, SCI being only one.

The findings of this study must be considered in the context of the health care system in Alberta, Canada, which is a public health care system. In Alberta, length of rehabilitation stay in the period between 1994 and 1999 for a person with a complete spinal cord injury was a median of 139 days³ as compared to 195 days in the Netherlands,³⁷ and approximately 71 days in the US.³⁸ The differential lengths of stays may have a profound effect on the readiness states of individuals with SCI, and the delivery options for information about prevention of secondary conditions.

Conclusion

Patient education and information availability across the continuum of care for people with SCI would help to facilitate long-term health. Further research is required to explore and evaluate the effectiveness of patient education delivery in the community as well as alternative strategies during inpatient rehabilitation. The primary health care initiative,³⁹ theoretically could help to provide better continuity of care for people with SCI because it emphasizes the prevention, promotion and management of health problems in coordinated comprehensive health system for people with long term conditions.³⁹ Nevertheless, in any system of care, the success of the care of people with SCI depends to some extent on the knowledge and skills of the health care professionals who work in those programmes. The concerns expressed by our participants about the (at times) limited knowledge of health care professionals about SCI will be addressed in a subsequent phase of this project.

This research proposes a framework that identifies areas to target in programmes designed to improve the long-term health of people with SCI. These target areas include health care professionals, readiness, contextual factors, and information topics and delivery. Collaboration between people with SCI, health care professionals, health care professional organizations (such as the physical therapy, occupational therapy, and medical associations), government (for planning of public facilities and for input into service delivery) is paramount to be able to appropriately target the identified areas to promote long-term health of people with SCI. A system that promotes linkages and rewards collaborations between care providers would be beneficial.

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