
Accessing Peers' and Health Care Experts' Wisdom: A Telephone Peer Support Program for Women with SCI Living in Rural and Remote Areas

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The unique needs of women with a spinal cord injury are not well understood, resulting in inadequate services. The Telephone Peer Support Group Program provided seven women with SCI living in rural and remote areas in Ontario with access to peer support and experts' knowledge. Participants were decision makers in all phases of the program. The phenomenological research method was used to capture the essence of their experiences. Two primary structures of experience emerged: emotional support and learning. Participants gave and received emotional, affirmational, and informational support, which resulted in different levels of reported change and transformation. The participatory approach contributed to participants' satisfaction. **Key words:** *community-based participatory research, community-based rehabilitation, peer support, spinal cord injury, telephone, women*

The Telephone Peer Support Group (TPSG) Program for Women with Spinal Cord Injury (SCI) Living in Small Communities and Rural Areas of Ontario, funded by the Ontario Neurotrauma Foundation, was developed as a response to a need expressed by aging women with SCI. It was designed and implemented in collaboration with seven women with SCI over the course of 20 months to assist them in managing their health and well-being. The main feature of the program was the participatory approach used to empower participants to make all program decisions.¹

The main goal of this research was to capture the essence of women's experiences of participation in the TPSG program and its main characteristics and structure as perceived by participants. The seven women with SCI contributed their narratives concerning their experiences and the usefulness and impact of the program. An examination

of the women's experiences of a TPSG program, which used a participatory approach, provides new information about possibilities for services for women with SCI and women with disabilities in general.

Literature Review

Women with disabilities are often under-represented in research and left without any opportunity to influence the services that

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are developed based on research with predominantly male participants.² Research has focused on men, because a majority of SCIs are sustained by younger men from violent causes, which result mostly in tetraplegia.³ McColl notes that recent epidemiological studies report an increase in the incidence of SCI, most often paraplegia, among older women.³ The unique needs of these women with SCI are rarely addressed in an appropriate way.⁴ Significant differences in the experience of aging have been reported in women and men with SCI.⁵ There has been a growing recognition that the interaction of disability and gender creates additional disadvantages and barriers to the full participation of women with disabilities in society.⁶

Persons with disabilities face difficulties in accessing primary health care.⁷ Their experiences with the health system are marked by a lack of access — to facilities, information, or knowledgeable professionals. This lack of accessibility affects the services women with disabilities receive and leaves a host of their health needs unaddressed.^{3,7,8} Pentland et al reported that women with SCI perceive that health professionals ignore and overlook their concerns and are unprepared or unwilling to address their specific issues.⁸ The same study revealed the feeling of profound isolation among women, in particular those living in small and rural communities, primarily due to environmental barriers, geographical isolation, and a lack of peer population. Women with SCI living in rural areas also reported experiencing inadequate health and rehabilitation services and spoke about their powerful need for interaction with peers.⁸ The literature on peer support describes its potential to meet some of the needs identified by these women, in particular for social support. Social support is con-

sidered an important determinant of quality of life for persons with SCI.⁹

Peer support programs have been developed on the assumption that persons with disabilities are experts in living with disabilities and that by sharing experiential expertise they can assist people in similar situations to overcome barriers.¹⁰ Peer support is an essential component of client-centered and community-based rehabilitation practice.^{11,12} It is considered an important source of motivation, support, camaraderie, mentoring, and practical advice for persons with disabilities. Campbell et al reported that peer support programs for cancer survivors have consistent benefits such as improving coping skills, sharing information, providing reassurance and a sense of normalcy, reducing isolation, and providing a better understanding of their experience and the future.¹³ The use of communication technologies to facilitate peer support groups has the potential to satisfy many needs of isolated individuals. Telephone peer support programs include one-on-one, professionally facilitated programs and programs that combine peer support with professional advice. Peer support programs do not diminish or replace professional services. In some peer partnerships, professionals have a role in the program as initiators, providers of information, and consultants who reinforce the values of independence and empowerment.¹⁴

Telephone support groups provide three types of support: emotional, affirmational, and informational.^{15,16} *Emotional support* helps participants deal with isolation through attentive listening, shared feelings and experiences, and expressions of solidarity and trust.¹⁶ This results in participants feeling accepted, cared for, empathized with, and respected.¹⁶ *Affirmational support* is positive

feedback, reassurance, and encouragement provided by group members.^{15,16} This support involves communication of optimism, motivation to persevere in problem solving, and assistance with self-evaluation, expression, and affirmation of the appropriateness of behaviors or emotions.¹⁶ *Informational support* is the most frequent type of support provided in groups by peers, facilitators, and guest speakers. It includes making relevant resources available to participants and sharing information that helps participants acquire new knowledge.^{15,16}

Stewart et al reported three anticipated mediating processes within telephone support groups based on the mediation model. This model predicts that peer support acts as an intervening variable, indirectly influencing health through emotions, cognition, and behaviors. These processes are social comparison, social exchange, and social learning.^{15,16} *Social comparison* allows participants to compare their experiences with those of peers to validate and normalize them, which influences their emotions and coping strategies. This self-evaluation offers opportunities for upward comparisons with role models and downward comparisons with those who seem to be worse off.¹⁷ *Social exchange* is about reciprocal supportive relationships that peers develop among themselves. Social exchange of experiential knowledge offers an opportunity for social learning in which role modeling and new learning take place. *Social learning* acknowledges the social learning theory in which people better assimilate new knowledge when it is presented by peers acting as role models and sharing their experiential knowledge.¹⁵

Over the last two decades the potential of telephone support services for persons living outside major centres has been recog-

nized and implemented internationally with various groups. Telephone peer support has been used among breast cancer survivors,¹⁸ persons with diabetes,¹⁹ Alzheimer's disease caregivers,²⁰ persons with multiple sclerosis,²¹ persons with melanoma,²² persons with hemophilia and HIV/AIDS,¹⁵ and couples coping with a cardiac condition.^{23,24} Aside from these initiatives, the telephone has not been used very often to reach isolated clients.^{25,26} No reports on telephone peer support for women with SCI were located in the literature.

The Design of a TPSG Program for Women with SCI

The TPSG program was designed in an effort to address the concerns about isolation from peers and lack of access to health-related information expressed in the telephone focus-group-based research by Pentland et al.⁸ The seven women with SCI living outside of major urban areas who did not have access to face-to-face peer support participated in developing the TPSG program.

They were recruited from the database of the previous research⁸ and through the Canadian Paraplegic Association. The following were inclusion criteria: (a) women with SCI, who were (b) at least 21 years of age, (c) living in the rural or small communities of Ontario, (d) with access to a phone line. Functional status did not preclude participation. **Table 1** summarizes the profile of participants.

The main goal of TPSG was to increase availability of peer support services in collaboration with women with SCI. The format provided easy access to relevant information and knowledge from eminent experts

Table 1. Profile of participants

SCI	Wheelchair	Age	Years since SCI	Independent in ADL (self-report)	Employed	Marital status	Size of community
Jane Tetraplegia	Yes	58	6	No	Retired	Married	1,800
Anne Paraplegia	No	43	5	Yes	Yes	Single	100,000
Claire Paraplegia	Yes	46	41	Yes with assistance	No	Married	14,000
Lydia Paraplegia	Yes	55	14	Yes with assistance	No	Divorced	9,000
Debbie Paraplegia	Yes	47	7	Yes with assistance	No	Single	150,000
Rose Paraplegia	Yes	47	5	Yes	No	Married	2,500
Stephanie Paraplegia	Yes	43	13	Yes	No	Married	4,000

Note: Jane, Anne, Claire, Lydia, Debbie, Rose, and Stephanie, agreed to participate in the program by signing the information and consent letter approved by the Queen's University Research Ethics Board. Pseudonyms are used to maintain participants' anonymity.

and peers in the topic areas that participants identified as priorities. The main feature of this program was that participants made all relevant decisions, which facilitated their empowerment. It created an environment in which women felt that they were listened to, taken seriously, and able to make an important contribution.

The program was implemented over 20 months in three phases: planning, implementation, and evaluation. In the first phase, women with SCI together with the program team identified their needs, set the priorities, decided on the implementation model, and established the criteria for the program evaluation. They also identified learning as

a main expectation and objective of the peer support group. They wanted to learn by accessing the latest resources relevant for their health and well-being and through peer support. Participants agreed on two types of teleconferences: (a) with expert speakers whom they identified along with the topics, and (b) through peer support teleconferences. They decided that all teleconferences were to be facilitated by an experienced facilitator. Consensus was reached in case of all major decisions, and the facilitator ensured that voices of all participants were heard.

To support participants' greater involvement in the program, the participatory development (PD) tools were used. These were

Table 2. Project timeline

Phase	Planning					Implementation											Evaluation and wrap-up				
Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	
Research events					RP															FG	I
TPSG	6 teleconferences: planning					26 teleconference: 11 peer support, 12 with guest speakers, 1 mid-term evaluation, and 2 planning teleconferences											3 teleconferences: 2 wrap-up, 1 evaluation				

Note: RP = research plan; FG = focus group; I = individual interviews; TPSG = Telephone Peer Support Group.

visual expression tools that were used during the planning and evaluation sessions to facilitate introductions, reach consensus, and encourage participants' creative expression. The PD tools included impact drawings/self-portrait, "fish and rocks" to identify barriers and enablers, a sorting exercise, and community mapping. Instructions for the use of the PD tools were mailed to the participants along with a return envelope several weeks before the teleconference. After completing the tasks, participants returned the sheets to the facilitator who copied the contributions of all participants and mailed them to the group in time for the teleconference.

Thirty-five teleconferences and one face-to-face wrap-up meeting were organized over the course of the program. Teleconferences included from two to seven participants per session. The average number of participants in the teleconferences was four. There were six teleconferences in the planning phase. Twenty-six teleconferences were held in the implementation phase, including 11 facilitated peer support sessions,

12 sessions with guest speakers, 3 additional planning sessions, and 1 focus group for the midterm evaluation. The final phase consisted of three teleconferences, including two wrap-up sessions and one focus group. **Table 2** gives the project timeline. More details about guest speakers and the topics can be found in **Table 3**.

During the implementation phase, participants made decisions about the timing of the sessions and recommended adjustments regarding the organization of the program, if necessary. The topics covered during the peer support sessions included accessibility, physical and attitudinal barriers, equipment and home renovations, relationships with people in positions of power, staffing, attendants and caregivers, overcoming trauma of the initial hospitalization and rehabilitation, advocacy, the information need, family relationships, time management, self-care, self-identity, the role of women in the society, physical activity; and motivation and weight control. Preparations for the evaluation started in the planning phase; one evalu-

Table 3. Guest lecturers and topics

	Guest lecturers	Topic	Location
1	Physician – physiatrist	Long-term SCI, joints and arthritis	ON, Canada
2	Physician – physiatrist	Recent developments in SCI research	MN, USA
3	Physician – gynaecologist	Menopause and women with SCI	ON, Canada
4	Physician – physiatrist	Maintaining health after SCI	ON, Canada
5	Physician – pain specialist	Managing pain	ON, Canada
6	Physician – physiatrist	Latest developments in SCI research	ON, Canada
7	Physician – physiatrist	Proactive health care	ON, Canada
8	Exercise physiologist, with SCI	Challenges and goals: living with SCI	CO, USA
9	Exercise physiologist, with SCI	Mind-body-spirit health care	CO, USA
10	Exercise physiologist, with SCI	Ideal scenes for personal health	CO, USA
11	Dietician	Nutrition and aging with SCI	ON, Canada
12	Physiotherapist	Physical fitness with SCI	ON, Canada

ation planning session was held to develop the evaluation framework with participants. The evaluation planning sessions as well as the midterm and final focus groups were facilitated by the researcher.

Methods

The qualitative phenomenological approach was used to illuminate the essence of the experiences of seven women with SCI who participated in the TPSG. Phenomenology aims to gain a deeper understanding of the experience by obtaining an insider's view of the phenomenon experienced, with the basic assumption that experience is knowledge.^{27,28}

Data were collected from the participants in three telephone focus groups at the beginning, midpoint, and end of the study and during individual interviews at the end of the program. An interview guide was developed to provide a framework for semi-structured interviews and was used flexibly to allow new issues to evolve. Focus groups lasted approximately 90 minutes, and individual

interviews lasted between 45 and 60 minutes. These were scheduled at a time suitable to participants and were tape recorded and transcribed. The researchers reviewed the minutes of all teleconferences prepared by the facilitator and the field notes taken during the focus groups and observed sessions. One researcher attended the final face-to-face meeting to share the initial findings with the group.

The experience of each participant was analyzed by using the phenomenological analysis according to Moustakas.²⁹ This analysis is a structured process of listing expressions and statements relevant to the participants' experiences of the program and refining and grouping them. Based on the statements grouped in the "meaning units," rich descriptions of individual experiences were developed of participants' perceptions of the program, its underlying structures, and what it meant to them. The final stage in the analysis was the development of a composite description of the meaning and essences of the experience for the group as a whole.²⁹

Trustworthiness was ensured by using

triangulation of sources and data collection methods. Data were collected until the saturation point where information began to be repeated and no new information emerged. The audit trail was maintained by keeping the details on all decisions about the research process. Member checks gave participants opportunities to check the accuracy of data and to affirm researchers' understanding and interpretations. Researchers reflected on and acknowledged the experience, attitudes, and beliefs they brought to this research.

Results

A composite description of the meanings and essences of the experience for the group as a whole is presented as a series of themes organized according to several universal phenomenological structures.²⁹ Although the themes are given under separate headings, they are deeply contextual and are linked to the women's individual experiences, their interactions, and the program as a whole.

Seventeen themes emerged as the core themes of the experience. The themes are grouped into four universal structures used in phenomenology: space, relation to self, relation to others, and causality in which participants linked the different levels of change with the program.²⁹

- A. *Space*: telephone peer support group program, emotional support, learning, participation in decision making, facilitator, telephone and participatory development tools
- B. *Relation to self*: isolation and loneliness, physical aspects of spinal cord injury, self-confidence, traditional role of women, being different
- C. *Relation to others*: support, care, com-

passion, and belonging; exchange of information and knowledge; comparison and validation; improving relations with others

- D. *Causality*: change, attitudes and knowledge, behaviors

This article reports only on key aspects within each of these universal structures that underline the essence of the experience. As reported by women, emotional support and learning were main structures of the experience permeating all other themes.

Space

For the participants, the TPSG program was a space that was safe for sharing, venting, laughing, connecting, exchanging, and giving and receiving emotional support. It was the space in which participants, who were peers, offered each other real understanding. Real understanding was based on shared experiences, shared abilities, shared challenges, and shared solutions.

You don't know exactly what I'm talking about. These people do. You don't even have to finish the whole line, they'll finish it for you, do you know? And that's huge. That makes you feel good that you can actually get it off your chest once in a while and somebody really understood and cared. (Stephanie, telephone interview, July 8, 2004)

Humor appeared to play one of the key roles in achieving this understanding.

We had some good moments in laughing and talking and chatting, and that helps in, to boost you, because when you've been on the phone, you do feel a lot happier, because you've talked to somebody, somebody who understands, and you've had this talk and this, the laughter with them, and the... (Lydia, telephone interview, July 5, 2004)

The program was also a learning site with easy access to peers and experts who had up-to-date and relevant information. The combination of peer support sessions and expert speakers worked well. Lydia found out relevant information from guest lecturers, but she was able to “get a lot of knowledge from the other girls.” Debbie shared the same feeling with the others about learning from peers. She also emphasized that learning from experts was relevant for her because “most of the information, I would say 90% of the information I found was geared directly at me.” To ensure the relevance of the program, it was necessary to give participants decision-making power over topics and guest lecturers. Stephanie’s learning was facilitated by the amount of specific information she received that was at her “fingertips” in the program. Debbie linked the relevance of the program with participation in planning: “I think as a group it’s very important [to take part in the planning] because you want the topics to be relevant to what you need.” By making them the decision makers in all phases of the program, it made the research highly relevant to them, unlike some of their previous research experiences, which did not mean anything and did not produce any results important for them.

“[This is] not just a little silly research blurb, it’s a big deal... They’re little one or two month things and they’ve been done to death. I don’t feel any much better at the end of them... There’s nothing to go with that, after the fact, where there is so much to go on this, this is massive... This is the biggest thing that I’ve ever been involved in. And this is the biggest thing out there as far as supporting our emotional being.” (Stephanie, telephone interview, July 8, 2004)

A good facilitator played an essential role in encouraging all participants to express

themselves, contribute to the program, and create a positive atmosphere of trust. The telephone provided a simple and accessible way for the group members to communicate. A lack of visual contact in getting to know each other was overcome by the use of the participatory development tools that proved to be invaluable, particularly in the introductory phase of the program. Some participants were reluctant to create drawings as they did not consider themselves “artistic,” but all appreciated the use of visual tools in facilitating connection and stimulating discussion.

Relation to self

The women’s experience of the program was closely linked to their sense of themselves. They became aware of the perceived conflicting identities of being a disabled woman and the caretaker of the family. They also remarked on the traditional role of woman in the society as a primary caregiver and questioned their ability to fulfill that role. Prior to joining the program, all the women felt profound isolation and loneliness. Some were struggling with the identity they had lost, both personally and professionally, when they acquired the SCI. The group helped Rose to find her new identity.

And you search for a new identity, because the one I had, and I can really only speak for myself, is completely gone. And I struggle to find a new identity. And that’s been a real mission for me. And I think because I had such a busy and incredibly full life before, it’s been hard to fill that void. But I’m now finding ways to do that, and I think the group has helped me... learn about those things as I listen to their experiences. It’s moved me to a final place I need to be in order to move ahead. (Rose, telephone interview, July 1, 2004)

The realization that some women with SCI do not have access to basic health services nor any other support was overwhelmingly frustrating for several participants. In addition to the social and emotional components of self, the women's physical experience of disability and disabling conditions defined their relations to self. A number of women considered pain to be their disability. Other health problems related to body mechanics and SCI were also prominent in determining their perceptions of self.

There was a strong sense of being different among women who did not share the same experience of the SCI with the majority in the group. The feeling of being different was caused by several factors: different activity limitations as a result of SCI (ambulatory vs. paralyzed vs. paralyzed with tetraplegia), different ages, and different lengths of time since injury. One woman perceived herself as being different from others because of her "double identity" as a peer and a professional counselor. The feeling of being different was closely linked to the ability of women to connect, relate, learn, and contribute. Although some women identified themselves as different, they were still able to relate to the group at some levels. Some of them recognized the universality of their experience of pain or the daily challenges of living with SCI, and this recognition allowed them to connect with other members of the group. The woman who had tetraplegia and was older than the others did not have the feeling of benefiting from the program as she felt that she was not connected to, supported, or understood by the group. She experienced difficulties participating in the telephone program, which raised the question of the appropriateness of the telephone for the delivery of peer support for persons with high levels of paralysis.

Relation to others

Participants' relations to others reflected the multiplicity of people with whom they interacted. These multiple others included the other group members, their families, health providers, community members, and other disabled people. Relationships among the group members were based on a strong sense of belonging, compassion, and care due to the shared experiences of SCI and feelings that "they are not alone" and that "they are all in the same boat."

The strength of this program right there is actually getting into the minds and helping the hearts of SCI people... Emotionally this has been the biggest thing for me... The strength is that there has been no other program out there or will be or has been, all the way along that has done so much for me... heart wise. (Stephanie, telephone interview, July 8, 2004)

Diversity within the group contributed to more dynamic interactions, improved understanding, and a greater appreciation of difference. Interactions within the group allowed participants to share their positive and negative experiences, to listen to others, and to be heard by others.

It was a very dynamic group. You had a good mix of people who have aged with spinal cord injury, and people who are new to the whole thing. So that made it really interesting, and that made it really that much more informative and... conducive to people actually getting more out of it. And, so the dynamics are great... You're able to learn more from everybody. (Anne, telephone interview, July 14, 2004)

Claire emphasized the importance of information exchanges because they were very specific, relevant, and shared "in a manner

that was really clear and understandable for me on a day-to-day level.” The program also gave participants an opportunity to compare themselves with others. Participants looked at those who were more self-confident, proactive, and outgoing as role models. Positive examples given by participants motivated others to have a more positive outlook, to accept health practices, and to adjust their behavior accordingly. The group members also served as a sounding board to each other to validate information, experiences, feelings, and attitudes. Group members were a source of information and practical knowledge for each other. All felt satisfaction from their interactions with other group members regardless of whether they contributed information, experience, a joke or offered compassionate ears and emotional support. They were aware that some information shared might not be correct and that potentially it could be harmful. Therefore, information exchanged in the group needed to be validated with professionals as well. Debbie summarized how she learned to be more empowered, resulting in the changed relations with her health care providers: “Now I have some participation in my own health.” Prior to the program, she felt like a passive recipient of health services.

Access to eminent guest speakers created learning opportunities and the possibility for participants to check information received from peers. Guest speakers gave information that was not easily available. Group interactions and access to expert speakers had an impact in on improved relations with family, health care providers, other peers, and community members.

[The program] affects the whole community when a few people are learning, informative,

concise information on how to live their daily life. That affects the whole community because then those people are more likely to feel capable in their community, to interact in that community, and to increase the worth of that community for the whole community. So it’s a wise investment of time, energy and resources to enable a whole community to grow. (Claire, telephone interview, July 10, 2004)

Improved relations with family, health care providers, peers, and community members resulted in women with SCI feeling more empowered, more proactive, and more in control. The sense of empowerment resonated with others, in particular, primary health care providers who trusted advice from the TPSG program that the women shared with them. In a sense, access to information they could trust made the providers feel empowered, as they were finally able to help these women resolve some of the important health problems significantly affecting their everyday lives.

When people have peer support and professional informational resources to deal with their daily life, they’re less likely to need serious support when they get into trouble because they didn’t have the information in the first place. (Claire, telephone interview, July 10, 2004)

It was clear from the participants’ comments that the facilitator played a key role in the “relations to others” aspect in terms of group dynamic and interactions. The facilitator in this case had experience in focus-group facilitation and research, including on women with SCI.

Causality

A majority of participants acknowledged some changes in their lives and attrib-

uted these to their participation in the TPSG program. The essence of the participants' experiences of the program was linked to their transformations. Participants reported more positive attitudes about themselves and about life in general as one of the more important changes they noticed. Each participant reported a different level of achieved attitudinal and/or behavioral change. Lydia felt that she remained lonely but the program increased her awareness of how to maintain her health: "Now it's made me realize, I think, that I need to be more proactive on my health." Participants noticed attitudinal changes and summarized them into an overall feeling of being more positive about, and more comfortable with, themselves. Claire "learned to be more forgiving, less critical of myself. More accepting, more content... thankful." She felt that the program gave her "even greater comfort to know that other people are struggling with the same issues every day." Anne realized that she had to "just more or less focus on the positive."

They found new identities that embraced both new and old selves. Some participants gained invaluable information and knowledge on proactive health practices and new services available to support persons with SCI. In relation to others, attitudinal change was manifested as having more respect and appreciation for different experiences. Participation in the program improved their peer support and communication skills, useful for volunteering in other peer support programs.

For some participants, the experience of learning in the group reinforced their commitment to plan and implement changes in their lifestyle that they perceived to be important for improving health and well-being, such as planning an exercise program and

annual check-ups with family physicians and other specialists. For others it meant taking control over their health, being more comfortable with themselves, and striking a balance between personal time and volunteering. Several participants changed their pain medication based on the pain expert's advice. Stephanie became more proactive and implemented a number of recommended changes, and she achieved good results: "The eating and exercise program has already been in place and, that's...that's proved big. I lost 25 pounds, I feel great." Stephanie felt that the changes she implemented were not temporary: "That's a life change that I've made for myself and my family." She also "followed through last summer with the three tests that I needed to have done for my health," and she booked them for the next year.

Rose launched the ProActive Spinal Network website, an on-line community for women with SCI (<http://www.proactivespinalnetwork.com/home.php>). The program gave her a final push in doing it. She did it for herself, for the members of the group, and all isolated and lonely women with SCI. "It's just something I've decided I'm going to do on my own because I have the knowledge, expertise, and the resources to do it. And I'm going to do it."

Discussion

Two main structures of experience, support and learning, and the participatory approach as a key characteristic of the TPSG program were discussed in the light of relevant literature. Participants in this study echo a general lack of research knowledge on unique issues of women with SCI. By emphasizing their satisfaction with the use-

fulness of the TPSG program for them, they expressed their dissatisfaction with other research, highlighting the need for establishing new partnerships that balance academic research agenda with usefulness and action for participants.³⁰

Support and mediating processes

The levels of support expressed by participants demonstrated that the TPSG program was successful in providing emotional, affirmational, and informational support as described by Stewart et al.¹⁵ The TPSG program was a safe and supportive environment for participants to belong, connect, interact, listen, empathize, and really understand peers who shared similar experiences.^{15,31} The identified themes also corroborate research findings on effectiveness of peer support in meeting emotional needs of consumers with HIV/AIDS and multiple sclerosis.^{15,21} The participants experienced the TPSG as a space where they received rounded emotional support, overcoming the neglect of women's emotional needs reported in the literature.³¹

Participants' relations with others were characterized by the morale boosting and encouragement they received from their peers during the teleconferences. The TPSG program was a space where they validated each other's opinions, experiences, and actions, described as affirmational support in the literature.^{15,16} Participants had increased access to knowledge and information from peers and guest lecturers, which in turn gave them a sense of empowerment. This confirmed the findings of other researchers, who stated that support in peer groups was most often informational support.^{15,16} Social comparison, social exchange, and social learning are reported in the literature as anticipated

mediating processes within telephone support groups. These categories describe the dynamic of this peer support group. Participants reported that the program gave them opportunities to compare themselves with others, those who were better and worse off; to validate their own experiences, attitude, and actions; and to learn from peers.^{15,16,23,24}

Learning

Learning was at the core of the structure of the experience of the TPSG program, as reported by participants. For each participant, the learning process was translated into a different level of change, including attitudinal and behavioral changes similar to those reported in the literature.³² This learning experience could be illuminated through a lens of a transformative learning process, because the changes they reported correspond to the stages of transformation as identified by Mezirow.³³ These included an opportunity for participants to express themselves, compare with others, and critically examine the ways they perceive the world. Peers and guest speakers presented a range of ways and opportunities for dealing with identified issues. The TPSG provided them with a space for reflective discourse in which they could also explore and test different roles and actions as described in the literature.^{33,34} Maintaining good health was a key concern for participants, as indicated in the literature on quality of life and life satisfaction of persons with SCI.^{35,36} A majority of the group members had negative experiences of the health system similar to those reported by Nosek et al and Pentland,^{7,8} and the TPSG helped them re-engage with the health system in an empowered way. It is important to note that health was also the main topic

of the learning process. Therefore, reported transformations were primarily linked to participants' health and well-being.

Participatory approach

Women with SCI who took part in the program highly valued the opportunity to make decisions about its design, implementation, and evaluation. This approach allowed them to develop the TPSG program suited to their needs and recognizing and valuing their priorities, which is one of key principles of the participatory approach identified in the literature.³⁰ Collaboration between the program team and participants was greatly facilitated by an extremely skillful program facilitator. She had exceptional organization and communication skills, an understanding of the main issues of women with SCI, and respect for their knowledge and experience, skills which have been recognized in the literature as essential in conducting participatory research.³⁷ Participatory development tools were successfully used in this program to initiate discussions, explore other ways of expression, and stimulate reflections. There is growing recognition of the role that creative arts can play in helping participants identify their strengths and weaknesses, map resources, and share their problems and concerns.³⁸

Study limitations

This study used a sample of convenience of self-selected participants. Although all participants experienced the phenomenon, and the sample size was within the range recommended in the phenomenological literature,²⁹ it would have been beneficial to use purposeful sampling, with a more homog-

enous sample, particularly in terms of type of SCI and length of time since injury.

Conclusions

The participatory approach is the key feature of the TPSG that allowed participants to be in control of the overall program direction, feeling that they could shape it to meet their needs in all phases. The TPSG program was a space where participants gave and received emotional support through sharing, connecting, and exchange. Participants who differed from the majority in the group because of the nature of their injury unfortunately did not benefit as much from the program. For peers, the program was a space of "real understanding," in which participants' perceptions of self was shaped and a new identity found, where loneliness was replaced with the feeling of belonging and "not being alone," where the bodily aspects of SCI and socially constructed roles of women were examined, where solutions for health and lifestyle issues were discussed and embraced, and where relations with others developed into the positive interactions of informed and empowered individuals. The TPSG program is an effective way to provide emotional, affirmational, and informational support. Women with SCI attributed changes in their attitudes and behaviors to their participation in this program. Reported changes ranged from increased knowledge about a proactive and healthy lifestyle to completed annual medical check-ups, changed pain treatment, changed dietary and exercise regimes, and the establishment of a website with information about a healthy and proactive life for women with SCI.

For the majority of participants in this program, the TPSG was reported to be an en-

riching and life-changing experience, which has a potential for reaching isolated women with SCI. For service providers, the program was an opportunity to service underserved populations, influencing their quality of life, health, and well-being, by using cheap and accessible technology. For researchers it was a rewarding experience of the usefulness of participatory approach, because immediate benefits were reported by satisfied research participants.

Implications for research and practice

All women in this study had an SCI, but resulting activity limitations were different. It is necessary for participants to share experiences, abilities, and challenges. Homogenous groups should be given preference, although different ages and length of time since injury could enrich the group dynamic. This is equally relevant for research and service programs. The telephone proved to be a good, simple, cost-effective, and easily accessible way of providing a peer support group program. Utilization of the phone should be explored further along with new computer-mediated groups using teleconferencing and videoconferencing

facilities. Another implication for research and services is the plea of participants and potential users of services to be engaged in setting the research agenda and designing the program. This will increase the relevance and usefulness of the research conducted for the people affected by it.

Areas of future research

In addition to investigating how participants of this program reintegrated new roles and perspectives into their everyday lives, there are three general directions for future research: (a) the effectiveness of the peer support programs on a larger population with SCI; (b) gender differences in experiences of SCI, needs, and coping strategies; and (c) outcomes of long-term TPSG programs on the health and well-being of persons living in remote and rural areas.

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