TELEPHONE PEER SUPPORT GROUP PROGRAM FOR WOMEN WITH
SPINAL CORD INJURY LIVING IN SMALL COMMUNITIES AND RURAL
AREAS IN ONTARIO: PARTICIPANTS’ PERSPECTIVES

by

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Abstract

This study was born out of the Telephone Peer Support Group Program for Women with Spinal Cord Injury Living in Small Communities and Rural Areas in Ontario, funded by the Ontario Neurotrauma Foundation. It represents the final chapter in the evaluation process of this innovative and participatory program, which produced positive results for a majority of women who took part in it. A phenomenological approach according to Moustakas (1994) was used to deepen the understanding and describe the participants’ experience of the program. The seven women who took part in the program contributed their narratives.

Emotional support and learning were the main structures of the experience as reported by the women. The 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 did not benefit as much from the program.

For true peers, the program was a space of “real understanding” and learning in which participants’ perceptions of self were shaped and new identities found, where loneliness was replaced with the feeling of belonging and “not being alone”. It was the space where the bodily aspects of SCI and the socially constructed roles of women were examined, where solutions for health and lifestyle issues were discussed and embraced, and where relationships with others developed into the positive interactions of informed and empowered individuals.
The women with SCI attributed changes in their attitudes and behaviours to 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, to the establishment of a web-site with information about a healthy and proactive life for women with SCI.

For the majority of participants in this program, it was an enriching and life changing experience which has a huge potential for reaching isolated women with SCI. For service providers, the program was an opportunity to provide services to underserved populations, impacting their quality of life by using cheap and accessible technology. For participatory researchers it was a rewarding experience of seeing immediate benefits reported by satisfied research participants.
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<th>Description</th>
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<tbody>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>CAILC</td>
<td>Canadian Association of Independent Living Centres</td>
</tr>
<tr>
<td>CPA</td>
<td>Canadian Paraplegic Association</td>
</tr>
<tr>
<td>PALS</td>
<td>Participation and Activity Limitation Survey</td>
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<tr>
<td>REB</td>
<td>Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board</td>
</tr>
<tr>
<td>SCI</td>
<td>Spinal Cord Injury</td>
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<tr>
<td>TPSG</td>
<td>Telephone Peer Support Group</td>
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CHAPTER 1

INTRODUCTION

1.1 Statement of the Problem

This thesis has its beginnings in 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. The peer support program was designed and implemented in collaboration with women with SCI over the course of 20 months. The main feature of the program was the participatory approach used to empower participants to make all relevant program decisions (Reason & Bradbury, 2006). The program can be described as an iterative learning journey in which participants had the opportunity to design and implement a peer support program which would meet their needs.

The main goal of this research was to capture the participants’ experiences of participation in this self-guided telephone peer support group program. In order to obtain a better understanding of the experiences, a phenomenological research method was used. The seven women with SCI who participated in the program contributed their narratives concerning their unique experiences, and the usefulness and impact of the program. This thesis aims to answer some of the key questions related to the essence of participants’ experience of the program, and the program’s main characteristics and structure as perceived by participants. It also provides insight into the importance and empowering effects of giving a voice to the voiceless.
Understanding the women’s experiences of a participatory peer support program provides new insights about the potential and possibilities for services for women with SCI, and indeed women with disabilities in general. Women with disabilities, including women with SCI, are very often under-represented in research, and left without any opportunity to influence the services and programs provided to and for them. Frequently, services are developed based on information generated in research with predominantly male participants (Krause & Broderick, 2004). This thesis contributes to the body of knowledge on peer support as well as the interaction of gender and disability as it focuses on women with SCI and engages them to look, themselves, for solutions that will improve the quality of their lives.

There has been a growing recognition that the interaction of disability and gender creates additional disadvantages, multiple oppressions and barriers to the full participation of women with disabilities in society (Hammell, 2006). The unique experience of disabled women has been largely ignored by the disability and feminist movements as well as by the research community, resulting in a limited understanding of their lived experiences, their needs, and the quality and range of services available to them. Experiences of disabled women’s contact with the health care system are marked by a lack of access, be it to buildings, equipment, information or knowledgeable professional services. This lack of accessibility significantly affects the services women with disabilities receive and leaves a host of their health needs unaddressed (Hammell, 2006; Nosek, 1997; Pentland, Walker, Minnes, Tremblay, Brower & Gould 2002b).

Women with SCI face the same barriers and discriminatory practices as other women with disabilities. Since a majority of spinal cord injuries are sustained by men, it
is very rare for the unique needs of women who live with SCI to be investigated or addressed in an appropriate way (Nosek & Walter, 1998). McColl (2002) notes that recent epidemiological studies report an increase in the incidence of SCI among older women. Women with SCI are an under-researched and under-serviced group, among the population with SCI. This calls for gender-sensitive approaches to addressing the issues of older women with SCI. Their issues are different from those faced by the majority of people with SCI, who are young men. In addition, significant differences were reported in women and men with SCI when it came to the experience of aging (McColl, Charlifue, Glass, Lawson & Savic, 2004).

Persons with disabilities in general face difficulties in accessing primary health care (McColl, 2002). Women with SCI perceive that health professionals ignore and overlook their concerns, and are unprepared or unwilling to address their specific issues (Pentland et al., 2002b). This study revealed the feeling of profound isolation among women, in particular among those of them who lived 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. Rural areas are generally under-serviced for people with disabilities. In addition, they spoke of their powerful need for support, and for interaction with peers, generally.

Peer support has been identified as an important source of motivation, mentoring and practical advice for persons with disabilities and as an essential component of client-centered rehabilitation practice (Cott, 2004). Social support is an important determinant of quality of life for persons with SCI (Anson, Stanwyck & Krause, 1993; Fuhrer, 1992;
McColl & Rosenthal, 2000). Peer support has been developed on the assumption that persons with disabilities are experts in living with disabilities and achieving their independent living goals, and that sharing experiential expertise can assist people in similar situations to overcome environmental and personal barriers (Canadian Association of Independent Living Centres [CAILC], 1992).

Peer support programs provide an environment in which sharing experiences, thoughts, concerns, fears and hopes is encouraged. A peer who can speak from personal experience often helps the person with a disability to gain a different perspective about her or his own situation (Cott, 2004; Payne, 1993). Contact with peers positively impacts the process of adjustment to the injury as the peer support group gives participants motivation, support and camaraderie, as well as opportunities for sharing experiences, and knowing they are not alone (Campbell, Phaneuf & Deane 2004; Payne, 1993).

The potential of telephone support services for persons living outside major centres has been recognized and implemented in a number of locations internationally with various groups over the last two decades. Telephone peer support has been used among breast cancer survivors (Curran & Church, 1998), persons with diabetes (Heisler & Piette, 2005), Alzheimer’s disease caregivers (Martindale-Adams, Nichols, Burns & Malone, 2002), persons with multiple sclerosis (Mohr, 2005; Payne, 1993), persons with melanoma (Rudy, 2001), persons with hemophilia and HIV/AIDS (Stewart, Hart, Mann, Jackson, Langille & Reidy, 2001b) and couples coping with a cardiac condition (Stewart, Davidson, Meade, Hirth, & Weld-Viscount, 2001a; Whittemore, Rankin, Callahan, Leder, & Carroll, 2000).
The use of communication and electronic technologies to facilitate peer support groups has the potential to satisfy many of the self-help support needs of isolated individuals. The systematic literature review of cancer peer support programs by Campbell et al. (2004) revealed that peer support programs have consistent and positive benefits such as improved coping skills, providing reassurance and a sense of normalcy, a reduction in isolation, information sharing, and a better understanding, both of the experience and of the future.

There are various telephone peer support programs including one-on-one, professionally facilitated programs, and those which combine peer support with professional advice and counseling (Lane, 1998). Aside from these initiatives, the telephone has not been used very often to reach isolated clients and increase the availability of services (Lane, 1998). No reports on telephone peer support for women with spinal cord injury were located in the literature.

During focus-group-based research by Pentland et al. (2002b) on the experiences of aging of women with SCI, the women repeatedly identified their feelings of isolation from peers and the lack of access to relevant, health-related information as issues they were facing.

The Telephone Peer Support Group (TPSG) program was designed in an effort to address these concerns. The seven women participants collaborated in developing the TPSG. Funding was provided by the Ontario Neurotrauma Foundation. The TPSG used a participatory approach to design a new and innovative way of providing group peer support over the phone. The format combined peer support and experts’ sessions with eminent guest speakers.
The participatory approach facilitated empowerment of the group of women who took part in the program. It created an environment in which women felt that they were listened to and taken seriously. They felt that they were making an important contribution in all phases of the program. The TPSG program provided participants with easy access to relevant and up-to-date information and knowledge from experts in the topic areas they themselves identified as priorities. This phenomenological study captured their unique experiences of the program and its impact on their lives.

1.2 Overview of Thesis

This thesis aims to present insiders’ perspectives on what it meant for women with SCI to participate in the Telephone Peer Support Group Program. Chapter One is devoted to introduction and overview. Chapter Two of the thesis provides a review of the current literature related to women with disabilities, peer support programs and participatory approach. Chapter Three describes the research methodology. This chapter opens with the description of the phenomenon under investigation, in this case the TPSG program, followed by the research question, and the rationale for choosing phenomenological research method to address it. It also includes descriptions of participants, procedures, ethical considerations, and rigour. Chapter Four describes the individual experiences of the program by each of the seven women who took part. Chapter Five presents a composite description of the experience for the group as a whole. Chapter Six discusses the findings in the light of current literature and study objectives and provides conclusions and implications for programming and research in this area.
CHAPTER 2

LITERATURE REVIEW

This chapter presents an overview of the literature which informed this study. The key areas which influenced this study are the current status of disabled women, in particular women with spinal cord injury (SCI), the topic of peer support programs and the participatory development approach.

2.1 Women and Disability

2.1.1 Disabled Women

In December 2007, Statistics Canada published the “Participation and Activity Limitation Survey (PALS) 2006: Analytical Report,” reporting results of a survey that collected data on 48,000 persons with disabilities. These were individuals who had limitations in performing everyday activities due to a health-related condition or problem. This national, post-census household survey reported that 4.4 million Canadians have activity limitations, representing 14.3% of population. This is an increase of almost 2% from the rate reported in 2001 and is the result of a number of factors including aging of the population and changes in reporting behaviours.

Adult women reported higher disability rates (15.2%) than men (13.4%). In general, the disability rate is slightly higher for women than men starting at age 25. The percentage of disabled women steadily increases with their age, reaching 57.8% among women aged 75 and over. Pain, mobility, and agility related disabilities, the most
frequently reported disabilities, are more often reported among women than men. A larger proportion of women than men reported more severe disability. Thirty-seven percent of all Canadian women aged 65 and over reported mobility limitations compared to 28% of men (Statistics Canada, 2007). With the population aging and women outliving men, disability is becoming an important women’s issue (Gerschick, 2000).

Disabled women internalize their concept of self largely through their body image, physical appearance, societal ideals of physical beauty, and gendered messages of how women should look and behave (Cassidy, Lord & Mandell, 1998; Zitzelsberger, 2005). Gerschick (2000) argues that bodies are central to the recognition of gender roles, as women and men. Disabled women are more likely to perceive themselves negatively than are disabled men. Negative body image contributes to the confusion over the sexuality of women with disabilities and this confusion is augmented by the absence of sanctioned social roles. Disabled women are stigmatized and considered asexual and role-less, conditions which further contribute to a sense of low self-esteem, self-alienation and powerlessness (Emmett & Alant, 2006; Fine & Asch, 1985; Zitzelsberger, 2005).

Many disabled people have been deprived of their rights to equal educational opportunities (Quebec Ministry of Employment and Social Solidarity, 2003). The situation with the education of women with disabilities is considerably worse than that of men with disabilities because of traditional perceptions of women’s social roles, negative attitudes and low expectations of women with disabilities (Cassidy, Lord & Mandell, 1998; Emmett & Alant, 2006).

A National Study of Women with Disabilities in the United States identified that (a) work opportunities, (b) availability of relationships, and (c) prevalence of abuse are
important factors that impact the sense of self in women with disabilities (Nosek, Howland, Rintala, Young & Chanpong, 2001). Persons with disabilities have higher unemployment rates than persons without disabilities (Brooks, 2005; Quebec Ministry of Employment and Social Solidarity, 2003). In comparison with both men with disabilities and non-disabled women, women with disabilities are much more disadvantaged when it comes to employment. Women with disabilities have higher unemployment rates than women without disabilities, and like men with disabilities are less likely to occupy well paid managerial positions (Williams, 2006).

Negative attitudes, stigma and low self-esteem shape expectations of family life for many women with disabilities. Women with disabilities are more likely never to marry, to marry later, or to divorce than women without disabilities (Cassidy, Lord & Mandell, 1998). The same study reported that if disabled after marriage, the divorce rate for women with disabilities is 99%, compared with 50% of men who divorce after acquiring the disability.

Childbearing by women with disabilities is discouraged because they are seen as dependent and unable to fulfill their mothering role. Women with disabilities face difficulties in finding health care providers who are willing to support them during pregnancy (Cassidy, Lord & Mandell, 1998; Nosek et al., 2001; Zitzelsberger, 2005).

Women with disabilities are more likely to experience physical, sexual and mental abuse, and for a longer period of time than women without disabilities (Emmett & Alant, 2006; Nosek, 2001; Young, Nosek, Howland, Chanpong & Rintala, 1997). Over 50% of women with congenital disabilities have been raped, sexually abused or assaulted (Cassidy, Lord & Mandell, 1998). The same authors state that negative body image and
perceived inferiority of women with disabilities were used by men as reasons for raping them.

The experience of disabled women’s contact with the health care system can be summarized as a lack of access to buildings, equipment, information and knowledge. Inaccessibility significantly affects the services women with disabilities receive and leaves a host of their health needs unaddressed. These needs include breast or cervical cancer screening for women with spinal cord injury, and sex education for women with mental health problems (Nosek, 1997; Nosek et al. 2001). Although this area of health research is in its infancy, the recognition that women experience their disabilities very differently from men is an important step towards creating better and more accessible health services for all women with disabilities. This recognition will drive the research agenda, increase understanding and ultimately improve the quality and range of services available for women with disabilities. Overall, the lack of knowledge related to women’s issues is evident (Isaksson, Skar & Lexell, 2005; Nosek, 1997).

There has been a growing recognition that the interaction of disability and gender (both socially constructed classifications) creates additional disadvantages and barriers to the social participation of women with disabilities. Women and men do not carry the negative impact and burden of disability equally (Emmett & Alant, 2006). For years, the disability and feminist movements as well as the research community have ignored the unique experience of women with disabilities. In recent years, the voices of women with disabilities have been getting stronger, resulting in more acceptance of disabled women among the feminist and disability movements and a recognition that women have a right to full and equal participation (Begum, 1992; Hammell, 2006).
The disability movement has made a significant contribution to the improvement of the quality of lives of persons with disabilities by promoting the social model of disability. This has been established today as the mainstream framework to understand disability as a socially constructed phenomenon (Lloyd, 2001). The movement was important because it raised awareness and highlighted how persons with disabilities were denied opportunities, excluded from mainstream society and discriminated against because of socially created barriers (Hammell, 2006; Morris, 1996). However, women with disabilities did not receive much attention within the movement. It was dominated by the male experiences of disability. This neglect translated into the under-representation of women’s issues in the disability movement and absence of women from leadership positions. Only in the last 20 years, have women’s issues gained importance within this movement and affirmative action has been introduced in Disabled People’s International so that women must be in 50% of leadership and management positions (Driedger, 1989). The United Nations Convention on the Rights of Persons with Disabilities (2006) has recognized the unique experiences and multiple disadvantages of disabled women by including separate clauses to deal with women’s issues.

The feminist movement has had an impact on many aspects of women’s lives, from reproductive rights and motherhood, to employment issues, to domestic violence (Hammell, 2006; Lloyd, 2001). Feminists exposed women’s experience in order to eliminate the inequalities that women faced in the society. Although they aimed to liberate all women, for years the feminist movement was concerned with sources of oppression of middle-class, white women. Feminist theory was developed based on the perspectives of privileged women and rarely included marginalized women (Cassidy,
Lord & Mandell, 1998; Ramazanoglu, 2002). Women with disabilities felt a deep sense of alienation from feminists without disabilities (Hammell, 2006; Morris, 1993).

Although they were not represented within the feminist movement, women with disabilities saw the relevance in the feminist perspective because it highlighted the issues that were at the centre of women’s lives. In an attempt to understand the interactions between the social constructs of gender and disability in the last decade the feminist movement has started to address the issues faced by women with disabilities (Lloyd, 2001). While both the disability and women’s movements have made significant progress, women with disabilities have not been integrated into, and therefore have not benefited from, either movement (Emmett & Alant, 2006).

In recent years women with disabilities have started to publicly share their experiences, needs and concerns. They have resisted oppression, fought for their rights and fought against exclusion, discrimination and prejudice (Hammell, 2006; Morris, 1996).

2.1.2 Women with Spinal Cord Injury

“To be a woman with SCI is to be a footnote in the field of medicine and research.”

(ProActive Spinal Network, 2007)

Women with SCI face the same barriers and discriminatory practices as other women with disabilities. The body of literature on women with SCI is even more limited because 80% to 85% of spinal cord injuries are sustained by men (Alexander, Hwang & Sipski, 2002; Samuel, Moses, Smith & Thorne, 2007). Although for many years there has
been recognition of the lack of understanding of women’s experiences of SCI, and recommendations for more studies to inform the development of gender sensitive services, very little research has been done in this area (Samuel et al., 2007). There is still a tendency to report data in aggregate, obscuring in this way the unique needs and experiences of women with SCI (Richards, Tepper, Whippie & Komisaruk, 1997).

The minority status for women with SCI among the overall population with SCI has an impact on the type and quality of health and rehabilitation services they receive. Services are designed based on the needs of a predominantly male population with SCI. This causes feelings of isolation, frustration and misunderstanding among women with SCI. Women with SCI report a neglect of their emotional needs during the period of rehabilitation (Samuel et al., 2007). Ability to maintain their health and well-being, their level of physical functioning and independence are prominent factors in determining the quality of life of persons with SCI in the community, in particular for those with a quadriplegic injury as it has more serious implications for one’s health and function (Manns & Chad, 2001; Noreau & Fougeryrollas, 2000).

Persons with SCI experience a number of changes in their health condition as they age (McColl, Charlifue, Glass, Savic & Meehan, 2002). A study by Pentland et al. (2002b) on aging women with SCI reported that women with SCI perceived that health professionals were unprepared or unwilling to address their specific issues. The same study reported that women with SCI had a sense that their key concerns related to psychological and sexual aspects of disability were ignored or overlooked by health and rehabilitation professionals and service providers. Another important finding of this study was that women felt profoundly isolated. The feeling of isolation was stronger among
those who lived in small and rural communities because of additional environmental barriers, geographical isolation, absence of peer population and adequate health, rehabilitation and peer support services. The perception of being in good health is among the key predictors of life satisfaction, two years post-SCI (Putzke, Richards, Hicken & DeVivo, 2002). Therefore, maintaining physical health when aging with SCI is one of the primary concerns of women with SCI (Estores, 2003).

In the study of women’s experience of SCI rehabilitation, Samuel et al. (2007) identified vulnerability as a central theme. They described vulnerability as feeling insecure, powerless and inferior. The same study identified that the feeling of vulnerability in SCI rehabilitation for women is exacerbated by their minority status, by a rehabilitation environment which lacks privacy, and by the perceived unavailability of rehabilitation professionals: their poor communication and autocratic style. Factors that eased feelings of vulnerability and increased feelings of security and self-worth were as follows: negotiating privacy, feeling reassured and encouraged and maintaining a positive attitude (Samuel et al., 2007).

Samuel et al. (2007) reported that rehabilitation staff helped minimize vulnerability by providing information about the physical condition and treatment, although information was not always adequate. Participants in other studies expressed their appreciation for the rehabilitation process, but they also felt that the system was not client-centered and that information was not always relevant and timely (Boschen, Tonack & Gargaro, 2003). Some theorists argue that rehabilitation professionals do not utilize a client-centered approach because it threatens their dominance over disabled clients during the rehabilitation process (Hammell, 2006).
Advice by others with SCI was considered crucial to adjusting to SCI and reducing the sense of isolation and vulnerability (Samuel et al., 2007). Male patients were seen as supportive, however, they found that the support offered by other female patients was uniquely valuable as it provided closeness, nurturing, kindness, sensitivity and mutual understanding. This corroborates the findings of earlier studies on long-term adjustment and community reintegration following SCI, in which social and peer support is regarded as invaluable for reintegration and an important factor in quality of life (Beedie & Kennedy, 2002; Boschen, Tonack & Garagar, 2003; Manns & Chad, 2001).

In summary, there is a discrepancy between the needs of women with SCI and the services they receive. Despite the identification of these needs and experiences, few investigators have occurred to further examine these discrepancies. Further research is needed to increase understanding of gender differences in coping with SCI and of the impact of peer support systems (Samuel et al., 2007).

2.2 Peer Support

2.2.1 Definition and Types of Programs

Peer is 1. a. A person of the same civil or ecclesiastical status or rank as the person in question; an equal before the law. b. A person who equals another in natural gifts, ability, or achievements; the equal in any respect of a person or thing. c. A member of the same age group or social set; a contemporary. 2. A person who is associated or matched with another; a companion, a fellow, a mate; a rival. Peer group is a group of people, esp. adolescents, of the same age, social status, or interests.

(On-Line Oxford English Dictionary, 2008)

Mead, Hilton and Curtis (2001) define peer support as “a system of giving and receiving help founded on key principles of respect, shared responsibility and mutual
agreement” (p. 135). Peer support is a mutually beneficial relationship, in which people identify with others they feel are like them allowing people to experience being who they are. Peers make decisions themselves and feel supported in achieving their independent-living goals (Mead, Hilton & Curtis, 2001). Although the experience of disability is unique for each person, many individuals find it very helpful to discuss their disability with someone who has had similar experiences. Peer support is a creative and non-judgemental way of thinking about disability and how individuals experience it. It helps people make meaning of their lives, in contrast to a medical model, which is based on classifying, labelling, diagnosing and correcting disabled people’s lives (Hammell, 2006; Mead, Hilton & Curtis, 2001).

Peer support has been developed on two main premises: (a) that many persons with disabilities have acquired unique experiences and expertise in realizing their own independent-living goals, and (b) that this experience and expertise could assist other people in a similar situation to overcome environmental and personal barriers to full participation in community life (CAILC, 1992; Mead, Hilton & Curtis, 2001).

Peer support programs provide a supportive environment of confidentiality and trust in which sharing experiences, thoughts, concerns, fears and hopes is encouraged. The fact that there is a peer who can speak from personal experience often helps the person with a disability to gain a different perspective about her or his own situation (CAILC, 1992; Mead, Hilton & Curtis, 2001).

Social relationships and support have been explored by many health and social scientists because they are perceived as important factors for the treatment of disease and the maintenance of health and well-being. Thurston and Meadows (2004) stated,
The social context, particularly relationships were very important for women’s health. Knowing and talking to women with similar experiences were highly valued as a mechanism for emotional and practical support, for evaluating and assessing the meaning of information for one’s own life (p. 103).

Peer support programs have been incorporated in the spectrum of available health services (Dennis, 2003a) for breast cancer survivors, persons with diabetes, multiple sclerosis, melanoma, hemophilia and HIV/AIDS, couples coping with a cardiac condition and Alzheimer’s disease caregivers. This indicates recognition of the vital importance of such programs for health. Internationally, peer support programs were successfully provided to landmine survivors and other disabled people in post-war environments (Peat, Edmonds & Jalovcic, 2002; Peat, Edmonds & Jalovcic, 2004).

A peer support concept analysis by Dennis (2003a) identifies multiple types, settings and providers of peer support interventions including one-to-one, self-help/support groups, on-line computer mediated groups, and telephone support groups. These may be provided in the home, a hospital, walk-in clinic, community organization, school, or prison. Solomon (2004) groups peer support into six categories based on the mode of service delivery: self-help groups, internet support groups, peer-delivered services, peer-run services, peer employees and peer partnerships. Solomon’s definition of the peer partnership describes the nature of the TPSG program. Peer partnerships are programs in which administrative responsibility for the program lies with a non-peer organization, governance is the shared responsibility of peers and non-peers, while the primary control over the program is with peers (Solomon, 2004).
Peer support services are usually provided by volunteers, paraprofessionals and professionals. Volunteers are trained in a variety of counselling skills such as communication, listening and empathy, problem solving, stress management, crisis intervention, and ethical and procedural issues associated with the program (Dennis, 2003a; Peat, Edmonds & Jalovcic, 2002, 2004).

Peer support programs do not diminish or replace professional services. In some peer partnerships, professionals have a role in the peer support group as initiators, providers of information, and as consultants who reinforce the values of independence, empowerment and the mutual aid of peer participants (Wilson, Flanagan & Rynders, 1999). Peer support services are flexible and address a range of different issues such as isolation and loneliness, body image and self-esteem, adjustment to a new disability, transition to an independent lifestyle, and information sharing on community resources and support services.

There is a range of peer support programs offered in Canada. The following are some examples of peer support programs by the Canadian Paraplegic Association (CPA) and the Canadian Association of Independent Living Centres (CAILC): one-to-one support (counselling and matching of participants and volunteers on several demographic and disability characteristics), peer support groups (face-to-face), web-based peer support, educational events such as personal growth seminars and workshops, and an informal format which allows for interactions between participants to be tailored to meet their actual needs (Hutchinson et al., 1997).

Face-to-face interventions, the most often-used way of delivering peer support, do not serve people well if the participants are geographically and socially isolated from one
another. Therefore, computer-mediated and telephone programs have been developed to target this population (Han & Belcher, 2001).

The British Columbia Paraplegic Association has a web-based peer support program called Peerzone. The aim of this innovative program is to provide opportunities for people with spinal cord injuries, their family members and friends to meet and interact with others who share similar experiences in dealing with issues related to living with spinal cord injury. On this interactive web-site they provide personal support and assistance ranging from discussing challenges to providing specific information on community resources and services. Although peer support is one of the core programs in CPA and CAILC and both organizations have developed a range of variations and innovative approaches, so far they have not used teleconferencing to provide group peer support services.

Telephone peer support has been used among breast cancer survivors (Curran & Church, 1998), persons with multiple sclerosis (Harris, 2000; Schwartz & Sendor 1999), hemophiliacs with HIV/AIDS (Stewart et al., 2001b), mothers at risk for postpartum depression (Dennis, 2003b), and couples coping with a cardiac condition (Stewart et al. 2001a). The telephone peer support group program was offered to women with breast cancer living in rural areas of Newfoundland and Labrador. They expressed feelings of isolation similar to the strong feeling among women with SCI living outside of major cities (Curran & Church, 1998). This program made available peer support to women with breast cancer through teleconferencing, thus facilitating support for geographically isolated individuals. Curran and Church (1998) reported that the use of communication and electronic technologies to facilitate peer support groups can satisfy many of the self-
help support needs of isolated individuals. Their study of breast cancer survivors showed that teleconferences provided an opportunity for women to share their experiences. They provided support for each other at a distance, overcoming in this way their isolation in their struggle with breast cancer.

A study by Harris (2000) showed that peer telephone support and a coping skills group intervention had similar effects on role performance, adaptability and well-being of consumers with multiple sclerosis. Another study of persons with multiple sclerosis examined the impact of peer support programs on five peer supporters with multiple sclerosis trained in active listening (Schwartz and Sendor, 1999). Analysis of data from quality-of-life questionnaires revealed that the peer telephone supporters showed pronounced improvement in confidence, self-awareness, self-esteem, and role functioning as well as an alleviation of depression. All participants articulated a sense of dramatic change in their lives in terms of how they thought of themselves and how they related to others. Although the number of participants in this study was small and the results cannot be generalized, the study showed that there were improvements in measures related to well-being.

Stewart and colleagues (2001b) reported that telephone support groups had a positive impact on meeting the support needs of participants in this pilot program that tested the feasibility of a telephone support group intervention for persons with hemophilia and HIV/AIDS and their family caregivers. They felt that they benefited from sharing information and that the support groups had decreased their feelings of isolation and loneliness. Participants also stated that the intervention should be longer than 12 weeks (Stewart et al., 2001b). Dennis (2003b) reported that telephone peer support may
effectively decrease depressive symptoms among new mothers, who were very receptive to the program and expressed high satisfaction with it.

The literature records many positive outcomes of peer support programs. Dennis (2003a) reports that modest attention has been paid to some potential adverse results including conflict, criticism, stress, reinforcement of poor behaviours, and lack of stability.

2.2.2 Types of Support and Mediating Processes

In studies of couples coping with a cardiac condition and hemophiliacs with HIV/AIDS, Stewart et al. (2001a, 2001b) defined three types of support provided by telephone support groups: emotional, affirmational and informational support. These attributes of peer support were further described by Dennis (2003a).

*Emotional support* is defined as support which helps participants deal with isolation through attentive listening, sharing feelings and experiences, expressing solidarity and trust (Stewart et al., 2001a, 2001b). Characteristics of an emotionally supportive environment include expressions of caring, encouragement, reflection, reassurance, advice-giving and avoiding criticism. This results in the experience of feeling accepted, cared for, empathized with, respected and valued, despite personal difficulties (Dennis, 2003a).

*Affirmational support* is positive feedback and encouragement provided by group members (Stewart et al., 2001a, 2001b). ‘Affirmational support’ in the literature is also referred to as ‘appraisal support’. This involves supportive communication that helps with self-evaluation and expressions that affirm the appropriateness of behaviours or
emotions. It also includes motivational mechanisms such as encouragement and assistance to persevere in resolving problems and finding positive outcomes, as well as the communication of optimism and positive expectations for the future (Dennis, 2003a).

*Informational support* is the most frequent type of support provided in groups by peers, facilitators and guest speakers. It includes information-sharing by giving advice, factual input or feedback that helps participants acquire new knowledge (Stewart et al., 2001a, 2001b). This type of support provides knowledge for problem solving by ensuring relevant resources are made available, alternatives are explored, and guidance about effectiveness given (Dennis, 2003a).

Stewart et al. (1998, 2001a, 2001b) reported three anticipated mediating processes within telephone support groups based on the mediator model which predicts that peer support acts as an intervening variable indirectly influencing health through emotions, cognition and behaviours. These processes are: social comparison, social exchange and social learning.

*Social comparison* allows participants to see the issue differently and compare their experiences with the similar experiences of peers. It allows participants to validate and normalize their own experience and adjustment. Its influence is on emotions and coping strategies. Social comparison provides opportunities for individuals to share commonalities in order to establish a sense of normalcy (Festinger, 1954). This self-evaluation offers upward comparisons, giving peers role models, optimism and something to strive for. It also gives opportunities for downward comparisons to those who seem worse off (Solomon, 2004).
Social exchange is about mutual and reciprocal relationships that occur within the peer support group. Social exchange of experiential knowledge offers an opportunity for social learning in which role modeling and new learning take place. Borkman and Shubert (1995) argue that people acquire knowledge better when it is presented by a peer, someone with whom they can identify and who shares common experiences.

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 (Stewart et al., 2001b). A study by Payne (1993) reported on the importance of contacts with peers in the process of adjustment to injury. Participants in this study identified the advantages of group learning as motivation, sharing of experiences, camaraderie and support from peers, as well as knowing they were not alone.

2.2.3 Peer Support and Learning

The processes of group learning in the telephone peer support group program may be examined through the lens of the transformative learning theory. Transformative learning is a constructivist approach to learning which is not a linear but an iterative, evolving and spiraling process (Taylor, 2000). It is a process of critical self-reflection which enables individuals to revise and develop new ways of seeing the world. Creation of new knowledge is a result of interpretations and reinterpretations in the light of new experiences. Transformative learning recognizes social interactions, emotional, interpersonal, cultural and social contexts and their importance in the meaning-making process. It is a complex process involving thoughts and feelings. It also involves an
interdependent relationship built on trust (Baumgartner, 2001). Transformative learning leads to change in beliefs, attitudes and behaviours. It allows participants to examine power relationships and limitations, preparing them to take action to free themselves from limitations they previously perceived as beyond their control (Nelson & Harper, 2000).

The process of perspective transformation starts with a “disorienting dilemma” which is often related to a personal crisis, such as acquiring spinal cord injury. This stage is followed by “self-examination” with feelings of fear, anger, guilt or shame, and a “critical assessment of assumptions” about an individual’s self and the world. Then, individuals engage in “reflective discourse,” in which they share their discontent, explore options for new roles, relationships and actions and obtain validation from others. Finally, action on this new perspective is imperative and includes planning a course of action, acquiring knowledge and skills for implementing one’s plans, provisional trying of new roles, building competence and self-confidence in new roles and relationships, and a reintegration into one’s life on the basis of conditions dictated by one’s new perspectives (Baumgartner, 2001; Mezirow & Associates, 2000). An environment that fosters transformative learning is safe, open and trusting in which participants can collaborate, explore, critically reflect and provide and receive feedback. This environment is challenging for rehabilitation professionals as it changes the traditional balance of power between professionals with expert knowledge and disabled people with experiential knowledge (Hammell, 2006). According to Hammell (2006) the best learning happens when people are helped to define their own problems, decide on solutions, and evaluate the consequences of their decisions.
2.3 Participatory Approach

TPSG program used a participatory approach to design, implementation and evaluation in order to ensure the program’s relevance to its participants as well as to create a supportive environment of trust, conducive to learning and empowerment. There is a growing body of knowledge about participatory approaches to research and practice, internationally (Reason & Bradbury, 2006). A majority of the literature appeared in the 1970s, and it was mostly linked to international development projects influenced by the work of Paolo Freire (1970). Freire made a significant contribution to literacy education for adults. This educational process was, in turn, the first step towards a critical examination of the social situation of these individuals. This then led to action to transform the situation. An important aspect of participatory development is that it is rooted in the social and political processes of knowledge-creation, which involves giving voice and power to marginalized groups (Gaventa & Blauert, 2000). Participatory principles and actions are used to democratize social change (Whitmore, 1998).

The key aspect of the participatory approach is that it requires collaboration of researchers, facilitators, and educators with individuals, groups or communities who are beneficiaries of the program (Cousins & Whitmore, 1998; Nichols, 2002). It is a participatory, cooperative and co-learning process leading to the exchange of knowledge, attitudes, skills and behaviours (Westfall, Van Vorst, Main & Herbert, 2006). Program stakeholders participate in all phases of its design, implementation and evaluation (Estrella, 2000). Burke (1998) emphasizes that in a participatory process, participants develop ownership over the program, improve their skills and build their confidence to change the program to better meet their needs.
Very often participatory methods are associated with visual tools or participatory development tools (Guijt, 2000). Blauert and Quintar (2000) suggest that visual tools are particularly useful in initiating participatory discussion and analysis. A range of participatory development tools were used in the TPSG program to increase creative and visual involvement of the participants in the planning and evaluation process (Narayan, 1994).

2.4 Conceptual Framework for Studying the TPSG Program

Based on the literature reviewed, a conceptual framework was developed (Figure 1) to illustrate how this study is situated within the current body of knowledge. It integrates the types of support provided in TPSG program with underlying mediating processes which result in learning and transformation.

The literature review highlights the complex needs of women with spinal cord injury and the diverse nature of peer support. The current expansion in peer support programs should be further documented and researched. Participants in these programs must take part in the design of research and evaluation to enhance the relevance of the program. Methods to consider are participatory action and narrative research methods (Mead, Hilton & Curtis, 2001).
The participatory nature of the Telephone Peer Support Program for Women with SCI provides an important opportunity to study a new and innovative peer support program for a group of women with SCI who have not been targeted in existing peer support programs and who reported geographical and social isolation (Pentland et al., 2002b). This thesis will contribute to a growing body of literature on peer support programs, casting light on a marginalized group of women with disabilities, those who live with SCI.
CHAPTER 3

METHODOLOGY

3.1 Phenomenon under Investigation

This study aimed to describe the essence of the experience of participants in a “Telephone Peer Support Group (TPSG) Program for Women with Spinal Cord Injuries Living in Rural Areas and Small Communities in Ontario.” The TPSG program, funded by the Ontario Neurotrauma Foundation, established a telephone peer support program for a group of seven women with SCI living outside of major urban areas who did not have access to face-to-face peer support groups. The main goal of the program was to develop innovative peer support services in collaboration with women with SCI, by using the telephone as a main mode of communication. Thirty-five teleconferences and one face-to-face meeting were organized and facilitated by a trained coordinator/facilitator over a 20-month period. The main objectives of the program identified in the project proposal were:

- To increase the availability and variety of peer support services by developing in collaboration with women with spinal cord injury a sustainable and cost-effective telephone peer support group program, primarily targeting women who live outside of major urban areas;
- To increase the capacity of program participants to develop and sustain similar telephone peer support group programs;
- To improve participants’ quality of life;
• To evaluate the program with participants and disseminate the results, and
• To replicate the telephone peer support program for other persons with SCI

The main feature of the program was that it employed a participatory approach,
giving the participants decision-making power over all relevant aspects of the program
(Reason & Bradbury, 2006). Participants made all decisions about the content, frequency
and delivery of activities and designed a program which combined peer support and
expert-led sessions, facilitated by the program coordinator.

During the planning phase, participants identified learning as a main expectation
and objective of the peer support group. They wanted to achieve it through: (a) peer
support – sharing and learning from peers, giving and getting support, and (b) increasing
knowledge and access to the latest resources (people, organizations, communities in the
research and service sector) relevant for their health and well-being.

Participants agreed on two types of teleconferences: (a) with expert speakers
(topics and speakers were identified in the planning phase), and (b) peer support
teleconferences. They decided that all teleconferences were to be facilitated by the
program coordinator/facilitator. Eleven teleconferences were facilitated peer support
sessions. There were 12 sessions with nine experts out of which six were physicians, one
psychologist/nurse educator, one dietician and one physiotherapist from Canada and
United States. Other sessions were used to plan, monitor and evaluate the program.

The participatory approach ensured a central role for the program participants in
the planning process. Nichols (2002) argues that a participatory approach helps to
empower participants, teaches them decision-making, communication and research skills and introduces a collaborative services approach. In order to encourage active involvement of women with SCI, the participatory development tools were used during the planning and evaluation phases. These visual tools included impact drawings and self-portraits, a needs assessment exercise called “fish and rocks”, a sorting exercise and community and home mapping.

As an evaluator of a participatory program, I was actively involved with research participants in all phases of the project. I participated in the overall program planning, facilitated evaluation planning sessions, facilitated a mid-term and an end-of-program focus group, conducted individual interviews, and observed teleconferences. Involvement of the evaluator and the participants in program planning provides an opportunity to integrate evaluation into the implementation and administration of the program (Nichols, 2002).

The program can be described as an iterative learning journey in which participants had the opportunity to design and implement a program which met their needs. It provided participants with access to peer support and experts’ knowledge about topics they identified as priorities for their health and well-being (Jalovcic & Pentland, 2007). A detailed program description can be found in Appendix A.

### 3.2 Research Question

To capture the essence of participants’ lived experience of the TPSG program, the main research question of this study was: “How did participants in the TPSG program experience and describe the program?”
Secondary research questions included:

- What were the things in this program that you would describe as its main characteristics?
- What was the essence of your experience of this program?
- What were the characteristics of the program that are appropriate or inappropriate for delivery of services for women with SCI in small and rural communities?
- What were the strengths and weaknesses of the program?
- How useful were the participatory development tools in the planning, design, implementation and evaluation of this program?

3.3 Selection of Methodology

There was a paucity of literature on women with SCI and their specific needs. In addition, there was no literature on telephone peer support group programs for women with SCI, either in Canada or internationally. Consequently, there were no established instruments to measure the success of such a program and its impact on women with SCI.

The number of participants in this program was small. Seven participants formed a very diverse group as they belonged to different age groups, each had a different functional status, and the length of time since they acquired the injury also differed. Creswell (1998) states that seven to ten participants offer sufficient information for a rich description of their experiences in a phenomenological study. Thus, this group of women with SCI was suitable for a qualitative, phenomenological study. Qualitative methods were selected to gain a deep understanding of the experiences of the women with SCI who participated in the TPSG program.
Qualitative methods are complementary to the participatory approach which was a main feature in all stages of the program’s development, implementation and evaluation. The participatory approach involved the collective examination, assessment and planning of a program by stakeholders and beneficiaries. Its emphasis on self-determination made this approach an ideal choice for use with women with disabilities. Nichols (2002) argues that a participatory approach helps to empower participants and teach them decision-making, communication and research skills and introduces a collaborative approach to services.

3.4 Qualitative Research Paradigm

Patton (2002) defines paradigms as “important theoretical constructs for illuminating fundamental assumption about the nature of reality” (p. 72). Creswell (1998) describes a paradigm as a set of basic beliefs, a worldview that defines the nature of the “world” and an individual’s position in it. A paradigm is associated with four sets of philosophical assumptions. These include ontological, epistemological, axiological and methodological assumptions.

3.4.1 Ontological Assumption

The ontological assumption answers the question: “What is the form and nature of reality?” (Creswell, 1998, p. 75.) Patton (2002) states that “constructivism begins with the premise that the human world is different from the natural, physical world… because human beings have evolved the capacity to interpret and construct reality” (p. 96).
Reality is constructed by those involved in the research (Creswell, 1998). Multiple realities can exist, as individuals create their own realities. These multiple realities constructed by people, and the implications of those constructions for their lives and interactions with others are investigated and reported in qualitative studies (Patton, 2002). Qualitative studies are characterized by inductive thinking, based on information provided by study participants.

3.4.2 Epistemological Assumption

The epistemological assumption deals with the relationship between the knower/researcher and what can be known/researched. It answers the question “What is the relationship between the knower or would be knower and what can be known?” (Creswell, 1998, p. 75.) This study fits within the qualitative paradigm, in which the relationship between researcher and research participants could be described as an interactive one. The researcher minimizes the distance between herself/himself and those being researched. This involves participation with, and observation of, participants over an extended period of time (Creswell, 1998).

3.4.3 Axiological Assumption

The axiological assumption is related to the role of values and the nature of ethics. It answers the question: “What is the role of values in research?” (Creswell, 1998, p. 75.) Qualitative study requires the researcher’s active involvement, and interaction between and among researcher and participants (DePoy & Gitlin, 1998). Given the closeness in relationship between the researcher and research participants, it is important in qualitative
studies to recognize that research is a value-laden process. The researcher actively reports her own values and biases. More details can be found in the sections 3.6 Ethical Consideration and 3.7.4 Reflexivity.

3.4.4 Methodological Assumption

The methodological assumption concerns the choices and use of an appropriate approach to the research and answers the question “What is the process of research?” (Creswell, 1998, p. 75.) Based on the research questions, characteristics of the sample, and research paradigm, the phenomenological research method according to Moustakas (1994) was selected among different qualitative methods.

3.5 Study Design

The choice of phenomenological research method for this study was inevitably tied to the main goal of the research: understanding the experience of participants in the telephone peer support group program. This choice was made because phenomenology is committed to understanding the human experience (Creswell, 1998). Phenomenology aims to gain a deep understanding of the nature of the experience of a phenomenon or program. It gives an insider’s view of the phenomenon that is being experienced. The basic assumption of this approach is that “we can only know what we experience” (Patton, 2002, p.105). Additionally, in phenomenology there is an assumption that “there is an essence or essences of shared experience” (Patton, 2002, p.106).

To gain full knowledge of how people make sense of the world, their experiences must be described, analyzed and compared, to identify the essences of the phenomenon
(Patton, 2002). A phenomenological approach “describes the meaning of the lived experience for several individuals about a concept or the phenomenon” (Creswell, 1998, p.51). Since the aim of this study was to reveal the insider’s view of the program, a phenomenological approach was suitable (DePoy & Gitlin, 1998).

### 3.5.1 Participants

All seven women who participated in the TPSG program took part in this research. Originally, they were recruited for the TPSG from the database of previous research on women with SCI by Pentland et al. (2002b) as well as through the Canadian Paraplegic Association. The following were inclusion criteria: (a) women with spinal cord injury, (b) at least 21 years of age, (c) living in rural or small communities of Ontario, (d) functional status did not preclude participation, (e) access to a phone line.

All participants agreed to participate in the program by signing the information and consent letter approved by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (Appendix B). An addendum to the information and consent letter was developed and approved for the purposes of this research (Appendix C).

All of the women had spinal cord injury. Six of them used wheelchairs and one was ambulatory. Of the six using wheelchairs, five had paraplegia and one had quadriplegia. The average age of the participants was 48.4 years, with a range from 43 to 58 years of age. A majority of participants acquired their SCI 5 to 14 years ago, with one participant living with SCI for 41 years.
They defined their level of independence in performing daily activities from fully independent (three participants), to independent with assistance (three participants), and one dependent on assistance. The self-reported level of independence impacted participation in the program. Specifically, the woman with quadriplegia had difficulties participating in the program.

All participants except one stopped working after their injury, and one took early retirement. Four participants were married, two single and one divorced. The size of their communities was very different, ranging from 1,800 to 150,000 inhabitants. Details of the participants’ profiles are found in Table 1.

<table>
<thead>
<tr>
<th>SCI Needs wheelchair</th>
<th>Age</th>
<th>YRS since injury</th>
<th>Level of independence in ADL (self-report)</th>
<th>Employment status</th>
<th>Marital status</th>
<th>Size of community</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Quadriplegia</td>
<td>Yes</td>
<td>58</td>
<td>6 yrs</td>
<td>Dependent</td>
<td>Retired</td>
<td>Married</td>
</tr>
<tr>
<td>2 Paraplegia</td>
<td>Yes</td>
<td>55</td>
<td>14 yrs</td>
<td>Independent with assistance</td>
<td>Unemployed</td>
<td>Divorced</td>
</tr>
<tr>
<td>3 Paraplegia</td>
<td>No</td>
<td>43</td>
<td>5 yrs</td>
<td>Independent</td>
<td>Employed</td>
<td>Single</td>
</tr>
<tr>
<td>4 Paraplegia</td>
<td>Yes</td>
<td>47</td>
<td>7 yrs</td>
<td>Independent with assistance</td>
<td>Unemployed</td>
<td>Single</td>
</tr>
<tr>
<td>5 Paraplegia</td>
<td>Yes</td>
<td>47</td>
<td>5 yrs</td>
<td>Independent</td>
<td>Unemployed</td>
<td>Married</td>
</tr>
<tr>
<td>6 Paraplegia</td>
<td>Yes</td>
<td>46</td>
<td>41 yrs</td>
<td>Independent with assistance</td>
<td>Unemployed</td>
<td>Married</td>
</tr>
<tr>
<td>7 Paraplegia</td>
<td>Yes</td>
<td>43</td>
<td>13 yrs</td>
<td>Independent</td>
<td>Unemployed</td>
<td>Married</td>
</tr>
</tbody>
</table>
3.5.2 Data Collection

In order to answer the research questions I collected data in multiple ways, during and following completion of the TPSG program. Data were collected over the phone, in both group sessions and individual interviews, as that was the setting in which the program was implemented. The in-depth individual telephone interviews were a primary data-collection method. Interviews lasted from 30 minutes to two hours. Two focus groups were organized to collect information about the participants’ experience of the program.

Focus groups and interviews were scheduled in advance and questions had been distributed to participants prior to the phone call, along with some paper and pencil tasks. General guidelines were developed for focus groups and interviews (Appendix D).

Table 2. Summary of Data Collecting Methods and Sources

<table>
<thead>
<tr>
<th>Data Collection Method</th>
<th>Source</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Individual interviews</td>
<td>Participants</td>
<td>End of Program</td>
</tr>
<tr>
<td>2 Focus Group</td>
<td>Participants</td>
<td>Mid-term, end of program</td>
</tr>
<tr>
<td>3 Observations</td>
<td>Researcher</td>
<td>During the program, Mid-term, end of program</td>
</tr>
<tr>
<td>4 Document review</td>
<td>Coordinator</td>
<td>On a casual basis</td>
</tr>
<tr>
<td></td>
<td>Coordinator’s journal</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Participants</td>
<td>Beginning, mid-term, end of program</td>
</tr>
<tr>
<td></td>
<td>Written reflections</td>
<td>On a casual basis</td>
</tr>
</tbody>
</table>

All data collection sessions were conducted in an informal and interactive way over the phone by using a semi-structured interview. Participants responded openly and
honestly as a good rapport developed over the course of implementing the TPSG program. A summary of data collecting methods and sources can be found in Table 2.

I was actively involved with the research participants throughout the project. I facilitated two evaluation planning sessions, mid-term and end-of-program focus groups, and conducted all individual interviews. Each focus group session lasted approximately two hours. Individual interviews were between 30 minutes and two hours in length. Focus groups and individual interviews resulted in approximately 15 hours of interview data.

I also participated in six general planning sessions, a wrap-up session and a face-to-face meeting at the end of the program; approximately 18 hours of involvement in planning and implementation of the program. I observed two sessions with guest lecturers and one peer support session and made field notes. This amounted to approximately six hours of observation.

I took field notes during the evaluation planning sessions, the focus groups and individual interviews, while the program coordinator generated the minutes of all other sessions. Participants were asked to use a number of different participatory development tools such as impact drawings, matrices, and maps, to provide additional insights. They were also asked to write their reflections on the impact of the program. The program coordinator kept a journal. Field notes, minutes, written reflections of the participants, the coordinator’s journal, and copies of visual tools used in the TPSG program were collected throughout the program and used as additional sources of data.
3.5.3 Data Analysis

Individual interviews and focus groups were tape-recorded and transcribed. Participants reviewed transcriptions of the individual interviews and sent their comments, confirming their agreement with the content. Over 260 pages of transcriptions were analyzed, initially. However, the phenomenological analysis was based primarily on the in-depth individual interviews with the seven participants. Data from other sources, including focus groups, were used to validate the findings of the phenomenological analysis of individual interviews.

There are several approaches to phenomenological data analysis, a method which “seeks to grasp and elucidate the meaning, structure and essence of the lived experience of a phenomenon for a person or group of people” (Patton, 2002, p. 482). The approach used in this study was guided by a detailed analysis developed by Moustakas (1994) as a modification of Van Kaam’s method of analysis. The first step in phenomenological analysis was epoche, a Greek word meaning “to refrain from judgment, to stay away from or abstain” (Patton, 2002). This is a way for a researcher to look inside, become aware and set aside personal biases, preconceptions, and prejudgments. Epoche is an ongoing analytical process which is followed by a phenomenological reduction, in which the world and pre-suppositions are “placed out of action,” bracketed out, so the data can be examined in pure form (Moustakas, 1994; Patton, 2002).

The experiences of each of the participants were analyzed by identifying and listing all expressions and statements relevant to the experience of the program. Each expression was treated as being of equal value. This stage in data analysis is called “horizontalization” (Moustakas, 1994). Data were coded and organized by using QSR
NVIVO 1.3 software (2000), by using open coding through the development of free nodes for each horizon.

A list of statements was developed for each participant through reducing and eliminating overlapping, repetitive, and vague expressions. These statements were invariant constituents of the experiences or horizons. They were compared in order to identify commonalities and the core meanings mutually understood by the participants through the program (Patton, 2002).

The statements were grouped into “meaning units.” Free nodes were organized into tree nodes in QSR NVIVO software. These first steps in the data analysis were done immediately after data collection had been completed for the program evaluation.

A draft evaluation report was prepared based on this initial analysis and presented to participants at a face-to-face meeting, which was the final event of the TPSG program. Participants’ feedback was actively sought at this point to ensure the accuracy of the initial interpretation, as well as of the consistency and completeness of data. Participants confirmed the initial analysis and identification of the main themes of their experience. Although the final event of the TPSG program was not optimal timing for a member check, it was an opportune time.

Since there was an extended period of time between the initial analysis and the development of descriptions of the experience, prior to embarking on writing I reviewed the literature on the methodology. I immersed myself in the data and started again from the *epoche*. Re-engagement began with my review of the scrap-book made during the face-to-face meeting, and was followed by reading all minutes, correspondence, personal journals and reports. Transcripts were read and re-read.
The description of phenomenological analysis by Moustakas (1994) as modified the Van Kaam method guided the analysis. Moustakas (1994) identified the following phases:

1. Listing and preliminary grouping,
2. Reduction and elimination,
3. Clustering and thematizing the invariant constituents,
4. Final identification of the invariant constituents and themes,
5. Construction of an individual textural description of the experience of each participant,
6. Construction of an individual structural description of the experience of each participant,
7. Construction of an individual textural-structural description of the meanings and essences of the experience,
8. Development of a composite description of the meaning and essences of the experience representing the group as a whole.

In the process of analysis I revisited many times the processes described by Moustakas (1994), seeking more clarity and direction on how to do phenomenological analysis. Phases used in this study included horizontalization, reduction and elimination, and clustering of themes. Meaning units for each participant were completed. A description of each meaning unit was made. These descriptions were used in preparing textural-structural descriptions, which are presented in Chapter 4.
Based on the clusters of meaning units, individual textural descriptions of the experience of each participant were developed, describing the program as perceived by the participants. This was followed by the construction of individual structural descriptions of the experience of each participant, through reflection and the use of imaginative variations, in order to seek all possible meanings of the program. A description of the underlying structures was also sought, as well as a description of how the program was experienced. Individual textural-structural descriptions were developed. The final stages of the analysis (Moustakas, 1994) were as follows: (a) the construction of an individual textural-structural description of the meanings and essences of the experience; and (b) the development of a composite description of the meaning and essences of the experience, which represented the experiences of the group as a whole.

3.6 Ethical Considerations

The TPSG program was reviewed by the Queen’s University Health Sciences and Affiliated Hospitals Research Ethics Board (REB). All women who participated in the program signed a letter of consent (Appendix B). An addendum to the letter of consent (Appendix C) was made and submitted to the supervisor/principal investigator for a review with REB, to reflect participation in the program evaluation process. Ethical standards were maintained by ensuring that the following ethical principles were applied:

- *Informed consent.* All participants signed the Informed Consent form agreeing to participate in the TPSG program. The Informed Consent form provided a description of the program and expectations from participants.
• **Confidentiality and anonymity.** All information collected and used in this study was strictly confidential. The anonymity of all participants was protected at all times. Tapes were transcribed and destroyed upon the transcription. Hard copies of the transcripts were kept in a secure location. Participants’ names were removed from all transcripts or visual tools and do not appear in any report or article. Pseudonyms are used in this thesis and other reports and articles.

• **Voluntary participation.** Participation in the study was voluntary. Participants were informed that they could withdraw from the evaluation at any point without any impact on their participation in the program.

• **Risks and benefits.** Risks and benefits were clearly identified and explained to participants prior to signing the consent to participate in the study. The risks identified were linked to the possibility of experiencing emotional stress during or after a teleconference call if a topic or issue came up that was particularly difficult for participants. One of the aims of the project was to give participants a chance to support each other on some difficult issues. However, participants had complete freedom to decide what they would share, if anything. There were no apparent physical risks related to the participation in this study. The benefits for participants were a chance to share and learn how other women were coping with SCI, and an opportunity to meet women with whom participants could keep up contact in the future, if they wanted. The aims of this project were to benefit participants directly, but also to obtain a better understanding of how best to facilitate peer support programs in the future for the women with SCI.
3.7  Rigour

A series of methods and procedures as outlined by Moustakas (1994), and DePoy and Gitlin (1998) were undertaken to satisfy the requirements of an organized, systematic and disciplined study performed with care and rigour. I was engaged in the TPSG program over an extended period of time (20 months), participating in and observing the program as suggested by Creswell (1998). Trustworthiness in this study was ensured by using the following strategies: triangulation, saturation, member checks, reflexivity, and audit trail (DePoy & Gitlin, 1998).

3.7.1  Triangulation

Triangulation is defined as the “use of multiple strategies or methods as means to strengthen the credibility of an investigator’s findings related to the phenomenon under study” (DePoy & Gitlin, 1998, p. 313).

Figure 2. Triangulation of Data Methods and Data Sources
Triangulation of data collecting methods and data sources allowed me to compare and validate information from different sources and methods (Figure 2).

3.7.2 Saturation

Saturation is described by DePoy & Gitlin (1998) as the “point at which an investigator has obtained sufficient information from which to obtain an understanding of the phenomena” (p. 312). The data were collected from different sources and by different methods to the point where information began to be repeated and no new information emerged.

3.7.3 Member Checks

Opportunities were given to participants on two occasions to review the accuracy of transcriptions and check and affirm my understanding and interpretation of data. The first one was immediately upon the completion of transcriptions. At this point, the transcripts were sent to participants. After reviewing the transcript of her interview one participant wrote to me: “Besides (me, not you) being long-winded. I think you captured the points I was trying to make. Thanks!” (Rose, personal communication, August 7, 2004)

The second opportunity was at the only face-to-face meeting, which marked the end of the TPSG program. Results of the initial thematic analysis were presented and discussed by participants as a part of the overall program evaluation. Participants were also given the draft evaluation report for their review and comments. No new themes were identified at that point.
3.7.4 Reflexivity: I, Evaluator, Participant, Instrument and Graduate Student

Due to the nature of the research, the population, the method and my role it is important to acknowledge the experience, attitudes and beliefs I brought to this research. The subtitle of this section illustrates the complexity of the role I played in this program. Occasionally it was challenging to balance them all. I became involved in this program because of my primary research interest in the interaction of gender and disability, and how this interaction influences women’s lives. The issues faced by women with SCI are close to me since I have a very good friend who sustained an SCI during the war in Bosnia and Herzegovina – and I see her now to be an empowered, inspiring and happy woman.

Research has shown women with disabilities are doubly disadvantaged because of their gender and their disability (Emmett & Alant, 2006). In many cases services for women with disabilities are designed based on research and information about men with disabilities. This is particularly true for persons with SCI as it is estimated that 80% to 85% of all spinal cord injuries are sustained by men (Samuel et al, 2007; Alexander, Hwang & Sipski, 2002). Very often women are voiceless when important decisions about their lives are made (Lloyd, Preston-Shoot, Temple & Wuu, 1996). I believed at the outset of this program that one way of improving the status of women with disabilities was to design – along with them – solutions that they believed would improve the quality of their life. I believe that in research and evaluation, this can be achieved through careful selection of methods, and facilitating the involvement of women with disabilities in all stages of the process.
Philosophically, I felt comfortable with qualitative and participatory methods primarily because of my cross-cultural work in international development, because both approaches were based on the direct involvement of participants in a number of stages of the research process.

My work experience has sparked my interest in these approaches. Too many times I have seen researchers or program developers coming to a group of vulnerable people, asking them questions for “higher scientific” purposes, extracting information, removing data from its informants, owners and sources, manipulating it and not giving anything back. “Subjects” become “objects” of the study without any control over what questions are asked or how the information they provide will be used, how truthfully it will be interpreted, and, ultimately, how they will benefit from the process.

I felt that this program provided an opportunity for women with SCI to participate in all phases of the program’s development, implementation and evaluation. It also allowed me to take part in all its phases as a participatory evaluator and instrument of data collection. This phenomenological study aimed to capture the women’s experience of the TPSG program. The use of a phenomenological approach defined my involvement as eliciting experiences, listening, analyzing and reporting the perspectives of the participants.

The selection of methods was driven by the need to ensure opportunities for women to participate and express themselves in different ways. I saw them as equal and important contributors and decision-makers, whose opinion was highly respected. This program provided learning opportunities for all of us involved, as well as opportunities to make changes in our program with the potential of having an impact on service planners.
and policy makers. It is my view that the selection of qualitative and participatory methods made sense in answering the research questions.

3.7.5 Audit Trail

I used the audit trail as suggested by Guba and Lincoln (2005), leaving a path of my thinking and coding decisions (DePoy & Gitlin, 1998), and documenting the process by preparing an evaluation report and written progress updates. Wolf (2003) identifies three parts of audit trail: raw data, data reduction and analysis products, and data reconstruction and synthesis. Examples of an audit trail used in this study are provided in Appendix E.
CHAPTER 4

RESULTS: INDIVIDUAL DESCRIPTIONS

In this chapter the experiences of Rose, Lydia, Debbie, Stephanie, Claire, Anne and Jane are presented in the seven narratives containing individual textural-structural descriptions (Moustakas, 1994). To respect anonymity of participants, all names used in this thesis are pseudonyms. The narratives are presented in the order of the interviews.

4.1 Rose

4.1.1 Biographical Sketch of Rose

Rose is a 47-year-old, married mother of two. She has been living with SCI for five years. She was hit by a drunk driver while she was cycling. She is independent in performing activities of daily living. Rose is a certified registered marriage and family therapist with a Master’s degree in counseling psychology. After her injury she stopped working as a therapist and she is still not employed outside the home. She looks after the family and lives in a village of 2,500 inhabitants, 20 minutes from a major urban centre.

4.1.2 Textural-Structural Description of Rose’s Experience of the TPSG Program

Rose’s experience of the program was characterized by true peer support, exchange and sharing. She described it as “great,” “wonderful,” “innovative” and “very creative.” For her, it was very important that the program served “older women”. She felt that the program was very user-friendly and easy to access. The regularity of its schedule and the familiarity of the telephone as a means of communication made the support group
“a breeze” to use. A good facilitator, with good counseling skills, good understanding of group dynamics and ability to “move traffic well,” deal with “problematic” members and inappropriate or unsafe comments was essential. In her view, at the core of the success of this program was the excellent facilitator who was very responsive to the group’s needs.

Rose was very sensitive to the group dynamic and discussed it with the facilitator on several occasions, developing a close relationship with the facilitator. She thought that it was very important to keep the group “vibrant” by ensuring good attendance. Rose believed that although providing audio-tapes of sessions was a good idea for those who could not attend, this might discourage regular attendance.

She appreciated an opportunity to participate in the design and evaluation of the program, reflecting that it was “frustrating when you participate in something and you can’t provide feedback about the design, and you know it’s not working and yet there’s no opportunity to say anything.” Rose stated that it was “cool to be able to say, ‘this works, this works well, this doesn’t work well’”. In her view, the participatory development tools were useful, in particular as a way to introduce members to each other. She felt that they could have been used later in the program again to generate discussions.

She felt that the contribution of guest speakers was very important to keeping the group functioning well over a long period of time. Rose was aware of the complexity of some logistical tasks, in particular the scheduling of the sessions with guest speakers. She acknowledged their busy schedules and the need for the group to learn “to be a little bit flexible when that’s required”.

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Guest lecturers gave us a focal point to kind of rally around. It gave us something to come to the group about to listen to and stimulate discussion. If you look at the needs of the people who come to this group, they are two-fold. They come here because they want information and they come here because they want support. And they got that because we could mix the two formats together quite well. But it required that input all the time. (Rose, telephone interview, July 1, 2004)

She considered the combination of discussions with guest speakers and support sessions was a good design to be replicated. It worked really well for this group. It provided access to information and knowledge that otherwise participants would not be able to access.

I think mixing the speakers and support was a great idea, and I would really encourage that that format in some way be continued. That worked well. Because so many of these ladies had never even had any of these things that were talked about, just hadn’t had exposure to it, so it was really neat. (Rose, telephone interview, July 1, 2004)

Rose spoke about the program in the first person, demonstrating that she really felt she was an active participant and a decision-maker, who had a strong sense ownership over the program. Throughout the program she showed a deep concern for her peers. Her great concern was that the program did not have a well-defined exit strategy to ensure a sense of closure for all participants. Rose explained her heightened sensitivity to the group dynamic by the fact that she was a health professional. She described herself as a bit “different” from other participants in this program as she felt she was both a peer and a health professional. Although she was the member of the peer support group, her professional self was also alert and monitoring the group dynamic and interactions during teleconferences. Both parts of her identity influenced her perspective. She commented on this somewhat complicated situation:
I’m in a bit of a weird situation in some ways, because being a health care professional myself, I can hear from two ears. I’m part of this group because I need to be part of that support group and that’s great for me. The other ear listens to the dynamics of the group, and so I have a bit of a different perspective perhaps. (Rose, telephone interview, July 1, 2004)

The profound impact of the program on Rose was realizing how little support there was for the women with SCI in their communities. She was “overwhelmed,” “floored,” she felt that it was “awful” that “because they sit in a wheelchair” participants cannot get even minimal, basic health care. The overwhelming realization about lack of support, “super motivated” her to share information and skills she had, with others living with SCI in Ontario.

And that has motivated me to do something, which I’m doing. So that will have, I hope, a fairly significant impact on the community of people who have spinal cord injuries in Ontario. So yeah, it’s done that. It’s super motivated me to do something with the information that I have and the skills that I have. (Rose, telephone interview, July 1, 2004)

She thought that the group deepened her understanding of the need for information and services and focused it, as she had been aware of it for quite some time in a “very unfocussed way.” She also felt that she should share her skills and knowledge with this community. Being a professional set her apart from others with SCI, even in early stages of her rehabilitation. She was aware that she was “different” and this group directed her towards a realization of how best to utilize her professional self and professional skills for the benefit of her other self, who belongs to a wider community of women with SCI.
I’m not sure it would have happened without it. I mean it was something that I always was kind of aware of, but in a very unfocussed way. I was aware of it while I was even in rehab, that I was very different than a lot of people who were in rehab, and I came out and I’m different than some of the people I’ve met who are in wheelchairs. And, so it only made sense for me to take, I have all this training, to do something with it that can support this community. And I think the group has helped me understand more specifically what that need is, and how I might go about doing something about it. (Rose, telephone interview, July 1, 2004)

The program encouraged her to continue focusing on the positive elements in her life, and to do as much as she could to advocate for, and support others. Her relationship with the others could be defined as one of genuine concern and responsibility for her peers. The peer support group and dynamic within it were of great importance for Rose. She described the group as “very open,” “receptive” and “supportive of each other.” She was concerned that some members would not critically examine advice and information shared by peers, since some of this information might be inappropriate or “medically unsound.” This profound concern for her peers was driven by her strong belief that the group must not “do harm.” She was also “really disturbed” by the program’s inability to support Jane, the only woman in the group who had a quadriplegia. Rose felt responsible to a certain extent for the program’s not meeting the needs of all members.

She “enjoyed being part of the group” and belonging to it. She considered her responsibility, her “job,” to be there for the group. Even the motivation to participate in this and other different groups was linked to her relationship to, and responsibility for, others. She described her motivation as two-fold. The first reason was to “improve herself by being open and trying new things”, and the second, to find out “if the program could help others”.

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Rose related her impact on the group to sharing her positive experiences with health and rehabilitation providers and encouraging some of the “very critical” and “very cynical” members to “re-engage” with the system to help themselves solve the problems they were struggling with. Her major contribution was to recommend speakers, health professionals who had personally helped her, who were good and who really did care. One example occurred when Rose shared with the group her positive experience with a pain specialist who had helped her. This made a difference to another group member, Stephanie. Stephanie was encouraged to try another option to manage her pain and this, in turn changed Stephanie’s attitude toward the health system.

I’ve been lucky enough to share with these people some of the great experiences I’ve had, and I hope that that’s allowed them to re-engage in the system, see some positive in it, become less cynical, be willing to, stretch themselves, try these things, and make their lives better. (Rose, telephone interview, July 1, 2004)

Rose also saw herself as someone who helped others focus on their strengths rather than weaknesses. The participants had a profound impact on Rose. She described changes at the personal level and in relation to others. Interactions with peers and sense of belonging were invaluable for changing her feelings about the challenges she faced in relation to living with SCI. She believed that it was impossible to resolve her issues related to SCI. However, discussing them, joking about them, sharing “war stories” and “sad feelings”, and venting her emotions helped her change her feelings about having SCI. The feeling that there are “other people like me” made her feel better.

Participation in the program assisted Rose in changing perceptions of herself and consequently influencing both her attitudes about herself, and expectations of herself.
The group helped her in the search for a “new identity” because her old identity was lost with SCI. With support from peers she reached the place where she needed to be in order to move forward.

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)

Although she could not accept the SCI as her new identity, with the assistance of the group she redefined herself and her new self was “more comfortable”, “more positive”, “more focused”, “more hopeful”, “more enthusiastic”.

I’ve learned to try not to be superman… Superwoman, you’re right. We’ve joked around issues of fitness and health and issues around home care, all sorts of issues. You’ve come to realize that I have to be more comfortable with more chaos in my life than I’m used to. And I’m trying to get used to that, because I was not a chaotic person before. And so but this life that we lead can become chaotic whether we like it or not. And so accepting some of that unpredictability, it’s just got to be there. I think I’ve learned to be more forgiving, less critical of myself. More accepting, more content… thankful. I’m really thankful. (Rose, telephone interview, July 1, 2004)

The new identity for Rose emerged from the recognition of the huge unmet needs of women with SCI in the community and the recognition of her own abilities, knowledge and skills to support them. In a sense, that new identity came from supporting herself while supporting other women with SCI.
An opportunity to compare with others and reflect on her own life filled Rose with the appreciation for what she had, her family and her husband. The mutual support and help exchanged in the program allowed Rose to break down the feeling of isolation she had experienced.

I don’t think we ever resolve issues. I think we discuss them, so that we might change our feelings about them. We can’t resolve the fact that we have bladder accidents or bladder infections or bowel accidents. Those things aren’t going to be resolved perfectly all the time, but in talking about them and in joking about them and in sharing our war stories and sad feelings, it somehow at the end of the day makes you feel as though there’s other people like me, and it can give me a moment to kind of vent all that frustrations and I feel better for it. (Rose, telephone interview, July 1, 2004)

In her relations with others, the group provided sense of empowerment by overcoming the powerlessness of “being in a chair” and opening ways for her to make “some difference in somebody’s life.” It also guided her to focus on the positive side of her life and refine her ideas on how to best support a community of persons with SCI.

I’m going to want to continue to focus on the positives in my life, because I’m really grateful for what I have. And I’m going to continue to do as much as I can to advocate and support people, whether they be in this group or others that I may come across in my life who are like me. I think helping each other is a real gift to each other. (Rose, telephone interview, July 1, 2004)

Finding a new identity, having a more positive outlook on life and really understanding the needs of women with SCI motivated Rose to take control and act. She established a website, “ProActive Spinal Network, an on-line community for women with SCI” to use her own skills, expertise and resources to provide information and support.
The web-site was the place where her old and new selves met, in an effort to help others. She found the necessary stimuli in the group to support other women with SCI, something that she had wanted to do but had not been able to focus the idea. She perceived the web site as this group’s joint work, as it had part of all of them, and it was as much theirs as it was hers. It channeled and practically expressed her personal and professional commitment to advocacy.

The group has helped me to focus an idea… I see this website as being as much them as it is me. The group super motivated me to do something with the information that I have and the skills that I have. (Rose, telephone interview, July 1, 2004)

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Structures that describe Rose’s experience of the program are expressed in her relations to herself as a woman with SCI, and as a professional counselor. This combination of personal and professional aspects made her a unique participant who had a dual experience of the program. She was a peer who gave and received support, and a professional who monitored the group dynamic and interactions. Relations with peers and the facilitator, and her strong sense of responsibility for peers dominated her experiences of the program.

The structure of the program and ease of access, its innovative combination of expert lectures and peer support sessions, regularity and flexibility created a dynamic and comfortable atmosphere. This atmosphere was characterized by trust, openness, receptivity and support.
Rose’s experience of the program was underpinned by her genuine concern for peers and a sense of responsibility to share with them her positive experiences of the health system. She was concerned for the well-being of peers and their ability to critically analyze and use peer advice. Her frustrations grew out of the inflexibility of the program, which made it unable to respond to the needs of all participants equally. She regularly informed the facilitator about her concerns and suggestions, developing in this way a unique relationship with the program facilitator.

Rose felt that sharing her own positive experiences with health services was an important contribution that she made to the group. She identified most of the guest lecturers and shared positive examples of health services provided by people who “really care,” breaking through the shell of cynicism she perceived in her peers, and encouraging them to re-engage with the health system in order to get the services they need.

This group helped Rose to win her struggle for “a new identity.” She felt that it helped her to move to the “final place” where she needed to be “in order to move ahead.” And that final place, that new identity for her, was the integration of her professional skills and personal interests in an effort to help others.

This group “super motivated” her to advocate. Rose established a website, which she called an “on-line community for women with SCI.” She was prompted to act by her belief that “helping each other is a real gift to each other,” by her understanding of the real needs of women with SCI and heightened awareness of the lack of services for this group of women.
4.2 Lydia

4.2.1 Biographical Sketch of Lydia

Lydia is 55. She acquired her spinal cord injury in a skiing accident 14 years ago. She uses a wheelchair to move around and is almost totally independent in performing activities of daily living. She receives support from caregivers three times a week to help her with some personal care. She also gets support on a monthly basis when shopping for heavier items. After her injury she and her husband divorced. She is a mother of two adult sons. She lives alone in a small community of 9,000. She is not employed.

4.2.2 Textural-Structural Description of Lydia’s Experience of the TPSG Program

Lydia was glad that she participated in the program, although she could not recall how it all started. The fact that some able-bodied people “cared” about people with SCI was amazing to her. She thought that the program was very good. It gave her an excellent opportunity to talk to other women with SCI who “understand” and to “vent about the system.” Talking to others was a “good morale booster” that “definitely picks you up,” especially on difficult days. Humour and laughter were very important to her:

I know now that it’s good to talk and be around women with spinal cord injuries. 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… even the venting about the system, it’s good to do that. So… it makes you happier at least somebody cares. (Lydia, telephone interview, July 5, 2004)
Lydia developed “a sense of belonging” to the group during the program, which she considered very important, in particular for isolated people living in rural areas. It broke her isolation temporarily. The program allowed her to be who she was, a “gentle soul,” an attentive but passive listener, and still benefit.

I like to listen rather than say a lot as well, so by sitting and listening I sort of got everybody’s opinions and was amazed at how they were so conscientious … [and] … proactive about their own health. (Lydia, telephone interview, July 5, 2004)

Lydia identified access to knowledge as one of the main strengths of the program. She pointed out that her peers had an incredible wealth of knowledge. In addition, a big strength of the program was the access to renowned experts whom the group members would not be able to reach, otherwise. Interaction with experts gave them more knowledge about the available services and where they should go to get them.

Irregular attendance was a concern for her. However, she was happy that the core group was almost always there. She considered core group members to be a group of three other women who started the program together with her and who had in common many issues related to their spinal cord injuries. The program design gave her opportunities to participate in the decision-making. However, she felt comfortable taking a less active role, as she felt the suggestions of other group members were good. She was very happy with how that worked. She did not like the use of participatory development tools. She had “a mental block” and felt insecure about the reaction of her peers.

Although she was aware that the program was time-limited, that was disappointing because she wanted to “hold on to the camaraderie of all the girls.”
“would really, really have loved to live nearer to all the girls,” to enable her to meet them more regularly.

Lydia’s experience of the program was marked by an ongoing examination of herself and her motivation to act and live in a certain way. A profound sense of loneliness permeated every aspect of her experience. That was repeatedly expressed as a need for interactions with friends with and without disabilities.

Comparison with other women with SCI who had a very proactive attitude towards their health and well-being made her feel “inadequate.” She was used to her “plodding along,” and dealing with issues as they come without any anticipation or preventive action. The knowledge and attitudes of other members made her feel that she was neglecting herself. Lydia self-reflectted after one of the guest speakers, who was a woman with SCI herself. Generally she “enjoyed her talk;” however, because of her assertiveness and determination, Lydia felt intimidated, “panicked a bit” and felt “pretty useless.” When examining her reaction to this speaker she thought that it was rooted in her own negative life experience with “Type A personalities” who expected everyone else to be like them.

Lydia pointed out that her life experience was an experience of “never been good enough.” She felt that her self-criticism and lack of confidence prevented her from doing things with “a flourish.”

When other people recognized her for her achievements in spite of her disability, she felt like telling them that there are other people who use wheelchairs who do much more. Generally, she put pressure on herself to be perfect and was always concerned about whether her thoughts and feelings were valid.
She attributed her passivity to her personality, but also to her initial experience of disability, which was a complete denial of her disability: “Nobody had to know that I was disabled. I couldn’t have any, anything out on show that I was disabled.”

She avoided being associated with other people in wheelchairs, and that was her way of coping with disability, and trying to live “a normal life.” She realized that was “wrong.” In addition to the denial of disability, her perception of women’s role in the society as primary caregivers, mothers and wives interfered with her need and ability to socialize with peers in the past. In Lydia’s view, women have more responsibilities for the house, their children and husbands and they do not have time to get together as a group to support each other.

Lydia’s relation to her peers was one of great admiration and affection for their knowledge, support, compassion, care and understanding. She thought that some of the women were “phenomenal” and that came as a surprise to her. With a great sense of humour she described two of “the most knowledgeable” peers:

I smile sometimes because I think they must have an office and a filing cabinet full of everything. They seem to keep everything. I read articles and I think, oh, I should keep that, and then they get lost. I have this vision of the two of them in their individual offices or places where their computer is, and files upon files of just information that, at their fingertips, and this energy to do it. That’s what amazes me about them, it really amazes me the wealth of knowledge that those two girls have…well both of them, it’s their career. It’s amazing that they’ve had the energy and the tenacity to make it that way. (Lydia, telephone interview, July 5, 2004)

Her interactions with peers were very fulfilling for her because they meant she belonged to a group. She learned from the group and she contributed to the group.
Although I don’t offer as much opinion as the girls that are more knowledgeable, I think I have little snippets of opinion and information that has helped. So I feel that it was worth helping somebody. (Lydia, telephone interview, July 5, 2004)

Lydia’s relation to others was a reflection of her relation to self: an ongoing examination and comparison. She reasoned that given her personal insecurities and lack of self-confidence, she constantly expected her peers to validate her views. Her only fear related to this program was whether her opinions would matter. That is the reason that she did not feel comfortable using the participatory development tools. She worried what the reaction of her peers would be and if she would look “silly.” The group highly valued her contribution and she felt good about this mutually helping relationship. Mutual understanding, and the fact that all group members did care about each other “to different levels,” were the most important aspects of Lydia’s relationships with her peers.

The program offered Lydia a wealth of knowledge and useful information about an active and proactive life with SCI. It offered her a secure place to share her problems, frustrations and achievements with a group of peers who really understood her. The understanding and caring of the group made Lydia more receptive and more positive about the usefulness of interactions with other women with SCI, as she had avoided them for many years.

At a very personal level she learned that there is more to people than meets the eye. She learned to be less judgmental about others through the interaction with one member who had an SCI, but did not use a wheelchair and did not have a visible disability. However, this woman shared many problems with the rest of the group.
She knew that she did not do enough for herself. She realized that she needed to “be more proactive” about her health. She learned what she should do to maintain her health. She received the latest information on types and availability of services she needed. Her awareness about health maintenance was increased.

Although the TPSG program put her in touch with her peers for an extended period of time, she felt that nothing had dramatically changed in her sense of isolation and lack of friendships. She continued to feel profoundly lonely and isolated, as she had always felt.

Illustration 1. Lydia’s Fish and Rocks

She felt that her biggest barrier to change was herself, as she visually depicted in Illustration 1, with what she deemed her strengths and barriers to achieving better quality of life. Being her usual self she blamed her “nature” and her “procrastination” for not getting more out of the program.
Self-reflection and constant comparison marked Lydia’s experience of the program. At the personal level, reticence and a lack of self-confidence determined her interaction with peers, and her level of participation in, and contribution to, the group.

The design of the program created for Lydia an environment of understanding and care with easy access to the latest and relevant information for her health and well-being. Although it was not “her nature” she shared her experience and information and had a feeling that it was worth contributing and helping others. Her primary role in the group was as a listener. She also shared her great sense of humour.

This group helped Lydia realize what she needed to do in order to maintain her health. From the personal experiences of others and from the guest speakers she learned about the services available in different health facilities and how she could access them.

Her knowledge and awareness of proactive and healthy lifestyles significantly increased. She knew what she was supposed to do. However, she did not notice any major change in her life, as she had the same feeling of isolation and lack of closeness with friends.

4.3 Debbie

4.3.1 Biographical Sketch of Debbie

Debbie is 47. She acquired her SCI seven years ago. She is single and lives on her own with a dog. Debbie is almost fully independent in performing activities of daily living. Currently, she is unemployed but lives a busy and dynamic life. She is very active in her community where she volunteers a lot for the Canadian Paraplegic Association and
the local committees. She is also back at school. She lives in a town of 150,000 inhabitants.

4.3.2 Textural-Structural Description of Debbie’s Experience of the TPSG Program

Debbie found the program to be very “satisfying” and “really interesting.” She really “enjoyed” it and “loved” it. Her initial fears that it would prove to be a group of women getting together and “grumping” never materialized.

Since leaving rehabilitation she has been trying to find information on women with SCI. Since women form a minority of people with SCI, there was limited research and “very little” information available. The program met her expectations of providing information in an easily accessible way. She felt that the speakers offered topics relevant to her experience of SCI, 90% of the time. The other 10% of the information was useful and she could pass it on to others when providing peer support. Debbie found almost all the information received from peers very helpful in some form, either for now, or for the future.

She felt the TPSG program was a good preventative program as it increased knowledge about necessary measures to maintain good health and provided information on how and where to get necessary services.

She linked the relevance of the program with the opportunity given to the participants to plan the program, select the topics and recommend speakers. Participation in program planning was very important to her as she was given an opportunity to express her concerns.
For Debbie, communicating over the phone was much easier than she thought it would be. “With the phone conversation you have, it almost feels like you’re there.” She found it a very convenient way to communicate in the support group.

The telephone is great. Everyone, pretty well everybody has a telephone, it’s easy to communicate with a telephone…With the telephone you can just sit and be comfortable and you can take notes. I have headphones so I can take notes, and talk on the phone. (Debbie, telephone interview, July 7, 2004)

She felt that on the phone “you can still be heard and listen.” “It was so easy to open up” to “total strangers.” Debbie felt that the anonymity of the phone helped women open up more easily and talk about personal problems. The teleconference sessions were “free flowing and easy, an easy chat” and she “never felt like” they “were being pushed.” She described the teleconferences as “an equal exchange of ideas” in a naturally flowing conversation without anyone’s domination. Humour was an important part of the group dynamic and made her feel good. Humour was a “great factor” in the group dynamic and Debbie liked to “crack a joke.”

The facilitator was good and helped move discussions along nicely and easily. At some point, when Debbie became friends with the other group members she wanted to meet face-to-face with them, knowing that might change the dynamic of the group.

Although she liked to express herself artistically she did not like to use the participatory development tools at the beginning. However, she discovered their advantages very soon during the introductory session when the self-portraits of participants helped her get to know them better and quicker. She thought that the visual tools were really great. When used later in the program they stimulated her to reflect
about the progress that the group made, and this gave her a great feeling of accomplishment.

Fitting the TPSG session into her busy schedule was Debbie’s biggest challenge and a source of her frustrations. Missing sessions upset her. She thought that more groups and more scheduling flexibility would help.

Debbie was sad that the program was coming to its end and she feared that moment. She was aware that women form a minority of people with SCI, and that there is limited research about women with SCI. She felt that camaraderie that exists among men does not exist among women with SCI. Although some women with other disabilities have similar problems, interaction with them is not as relevant as interaction with peers. Therefore, Debbie felt that it was important to share her positive experiences with other women with SCI in the hopes that the program would be continued and expanded to all those who need help.

The years following Debbie’s injury were marked by a frustrating and lonely search for information and solutions to her numerous health problems. The combination of experts’ and peers’ advice in the program helped her take control over her health and become a more equal participant in her treatment, rather than the passive recipient of health services. She resolved some long-standing health problems by using the advice and information from the program. These problems had significantly impacted her daily life and finding the solution resulted in an improvement in her overall well-being. She felt “much better” about her “overall health.” The group boosted her morale in general. She just felt better about herself.
‘Becoming more proactive’ is the best way to describe how Debbie thought about herself. She claimed that she became “more proactive regarding my well-being and myself,” and a bit “more proactive” about disability issues. She drew strength from the fact that her concerns were also the concerns of other women with SCI. She was not alone; she was not the only one voicing dissatisfaction. Others shared the same concerns as they experienced the same difficulties. The group validated her views and feelings and encouraged her to speak up. In her words, she “learned so much.” After meetings she felt “rejuvenated and strong.” For her it was good to participate and “just get the vibe, from all the other girls, of being strong.” She felt that the meetings were empowering. “Empowerment, that’s what it gives you.”

Debbie’s relation to the other group members was underpinned by her strong sense of belonging to this group which shared her experience. She felt that there were no barriers between them because they all had a “common denominator.” They were “all in the same boat.” Their interactions during the teleconferences deepened their connections. As they talked more, they found more common experiences. Debbie considered it extremely important that a number of isolated women got together. This gave them:

… the feeling of not being alone, and having six or seven girls that were all, experiencing either the same things, knowing that they were not alone. (Debbie, telephone interview, July 7, 2004)

Knowing that there were others experiencing same difficulties lifted

… a lot of the frustrations of everyday living because lots of times you think you’re the only one having these problems. (Debbie, telephone interview, July 7, 2004)
The fact that there were others there with same problems did not eliminate Debbie’s struggle, but it made it much easier.

The guest speaker with SCI made a great impression on Debbie, and the session made her feel stronger and empowered:

It’s great to see another person, a person that has spinal cord injury achieving so much. And, she has so much valuable information. That gave me a sense of empowerment because it’s, hey, she can do it, so can I… And getting the information that was relevant to what I needed made me feel that much stronger because now I’m on the right track. (Debbie, telephone interview, July 7, 2004)

The TPSG gave Debbie a sense of common ground with other women with SCI of her age. That gave her an opportunity to exchange experiences with her peers, compare with them, learn and validate her own status by knowing that she was “on the right track of things.” For Debbie, even talking to other women was sufficient to make her feel better. She felt that she was also contributing to the group by sharing information and knowledge about where to go for some services.

The members of the group could “really understand” each other because they had shared experiences. They were empathetic and commiserated with each other. Family members and friends, no matter how close, could not understand the women’s situation as they could not relate to the women’s experiences. However, interactions with her peers actually lifted some pressure from Debbie’s relationships with family and friends. For example, she stopped talking with friends about her SCI and had other conversations with them that she was “supposed to have with friends.” All group members offered a lot to the group, shared their good ideas “regardless of who they were or what they were or
where they were.” She felt uncomfortable that Jane, the only women with quadriplegia in the group, could not participate because of her difficulties.

Debbie felt that the TPSG impacted her role in, and interactions with, the community. She was able to speak up for herself and “help get some things changed that need changing.” The program helped her be a vital part of the community as a whole.

However, the biggest impact of the program was on her health, as Debbie took control over her health and pulled it together. She felt that now she could live a much healthier life because of the group. The biggest impact of the program was on her knowledge about her health and how she could be more proactive to maintain it. Since her injury, she had suffered from a problem related to women’s health that nobody could resolve. During menstruation, she was incapacitated, not able to participate in any daily activities. She had consulted her family physician, gynecologist, physiatrist, and the internet, and nobody had the solution.

During a peer session, she got a hint in a casual conversation that she further explored with the guest speaker and her own doctor and found a solution for a major problem in her life. The group also shed new light on some difficult issues facing women with SCI as they age. Eventually, they face the possibility of having to live in nursing homes. Instead of looking at this as a depressing event, Debbie began approaching this eventuality from a more proactive stance, planning in advance, taking control of the process and changing things if necessary.
Debbie’s self-portraits at the beginning and the end of the program illustrate the difference the program made in her life. The portraits depict the same Debbie, busy as always, doing all the things she likes to do. However, the “rejuvenated” Debbie is not “floundering away” in a middle of nowhere. At the end of the program she is off the “rough path” and on the “right path,” looking better and having the support just a phone call away. She described the change:

My family commented how much I have improved health-wise. I feel better about myself and my looks improved. (Debbie, telephone interview, July 7, 2004)

On other occasions the group helped her “put the puzzle together.” Bits of information about different issues came nicely together in practice. Debbie thought that the program had a positive impact on others as well. As an example she mentioned the change she noticed in Lydia, who became much stronger and much more outspoken than she was at the beginning.
For Debbie, this program was very important because it brought together women with SCI, and hopefully with a “united voice” that would be able to do things faster, influence the research agenda, or produce a book with information on women with SCI.

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Debbie’s experience of the program was marked by a significant improvement in her health status, a direct result of what she had learned through interactions with peers and guest speakers. Being proactive was the name of the game, for her. She became more proactive in relation to her health, to her role in the community and her future.

She found the program easy to access and very relevant to her experience of SCI. Both peer support session and guest lecturers were great sources of information about what she needed to maintain her health, and how and where she could get what she needed. The program was a common ground, a space shared with peers who really understood the problems and challenges she was facing, with whom she could laugh and empathize.

She learned a lot, but she also felt that she offered the group useful information. She noticed the change in her peers, as Lydia become a stronger and more articulate in her views. She shared her concern that the program could not help Jane.

The group put Debbie on the “right path” by helping her resolve some major health issues, and giving her bits of information to put the puzzle of daily living together. It also gave her a strong sense of belonging to a community of women with SCI.
4.4  Stephanie

4.4.1  Biographical Sketch of Stephanie

Stephanie is the 43-year-old mother of two young children. She was injured 13 years ago in a car accident. She is independent in performing activities of daily living. Some family members have told her that she is “overly independent”. Stephanie lives with her husband and children in a small rural community of less than 4,000 inhabitants. She is “stay-at-home mom” and a “domestic engineer” and does not have paid employment outside her home.

4.4.2  Textural-Structural Description of Stephanie’s Experience of the TPSG Program

Over the last 13 years, all her experiences with research programs have been disappointments for Stephanie. They left her feeling abandoned, empty or more depressed than she was when she started. Skepticism was her emotional and attitudinal starting point when she joined the TPSG program. At the beginning of the program she thought that it would be “another one” of those studies where she would pour herself out and would “not receive anything to benefit” her. However, she became intrigued by the way participants were empowered to decide where the program would go, what topics would be discussed and which speakers would be invited. The curiosity of “Can we really do this?” made her return to the group meetings. Her experience turned out to be quite the opposite of what she expected. She was “pleasantly surprised” as she “got so much out of it.”
Even at the beginning it was sufficiently interesting to explore opportunities of what the group could do and what speakers they could have. When it all came together, Stephanie felt that it was “phenomenal” what the women got out of the program. Stephanie described participation in program as:

Very, very. Very satisfying. I don’t think there’s anything, that I could compare this to in the last 13 years of injury that has been this emotionally satisfying. I can say this with, positive, there just has not been anything that emotionally satisfying for me. (Stephanie, telephone interview, July 8, 2004)

The ability to decide the content of the program attracted Stephanie. The program was exactly what she wanted it to be. She had “a good time,” and she was, overall, very impressed by the program. It was not just another “little silly research blurp” that did not go anywhere, and that she could not see any results from. She thought that this was really significant, as it impacted positively all participants.

The TPSG provided “rounded” emotional support as it gave the group the space for sharing their feelings among women who could “really understand.”

It was a nice feeling to know that you could go there and you could pour your heart out and one at least if not all, understood exactly what you were saying. Not kind of getting the gist of it, as a standing person would, but somebody that really understood that exact same thing that you’re saying they just did it that morning too…. I just had to be able to open up to somebody and have them really understand, not just kind of understand… the fact that you, you have somebody that totally understands what you’re talking about. (Stephanie, telephone interview, July 8, 2004)

At the core of Stephanie’s experience of the program is a feeling of “being understood.” She felt that she could unburden herself and the other participants would
know exactly what she was talking about. She emphasized that in order to understand, one really had not “to walk a mile in my shoes” but to “roll a mile in my wheels.” She felt that the group members really understood her and cared about her so she was able to “get it off her chest.” For Stephanie, the participatory development tools were invaluable in creating this atmosphere from the very beginning of the project, as they facilitated quick introduction and “warming up” of participants to each other. After teleconferences Stephanie felt energized, “good,” “plumped,” “perked up,” “elated” and “more positive.”

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)

Access to, and quality of information was invaluable for Stephanie. She had never had so much information which was relevant, up-to-date and specific to her SCI “at her fingertips.” She learned a lot of important information about health from the speakers. Stephanie treasured the tape records of those sessions.

These tapes are coveted, they’re on a high spot in my place, they’re coveted. There’s a lot of info in there. (Stephanie, telephone interview, July 8, 2004)

The sessions offered a lot of information that Stephanie had already used, and that she knew she would use in the future. The telephone was a good way to pass on information and she felt it could be used in the future, addressing the shortage of doctors in many areas. Stephanie and other group members were very much aware of the
uniqueness of this opportunity, having so much time from the experts and specialists who spoke with them. She thought “that was huge.”

From the group members she learned patience, a little bit of calm and quietness. Conversations among peers and exchange of experiences provided solutions for problems even when individuals did not seek them. They came in a natural way. She also learned from the facilitator, who had the ability to move things along, and made a “more natural” and “homey feeling” in the group.

Stephanie felt disappointed when other women could not participate because she always looked forward to “everybody’s voice” and she missed the ones who were not there. Attendance could be improved by ensuring that everyone had many opportunities to express their needs.

She will miss the program very much, as it became a part of her monthly routine. She expressed a concern about how other women from the group would cope after the end of the program, especially those women who were not as busy as she was. She was also concerned about women with SCI who were not in this project and who were deprived of the benefit of it. She saw huge potential in this program that could be applied “province-wide, Canada-wide and US-wide.”

It’s filled everybody up in so many ways. There’s no way anybody can’t say this is the biggest positive, the brainstorm of the year, the decade. I’m serious, I just want to get that point across. I am gonna take this away on my opinion. I want them to know it is the biggest thing that’s ever been created so far. I want them to go, I want them to run with it. I want to be running with it. I want to be involved in the middle of it. It’s great, it just makes you want to feel, it makes you want to feel like dial up and get everybody on line. It just makes you want to reach out and touch right across the provinces and get everybody connected and feeling this way, feeling positive and good and uplifted and happy and non-lonely. It does, it does something positive for you. (Stephanie, telephone interview, July 8, 2004)
Stephanie saw this research as a much bigger and more important than any of the numerous “cranberry fixes” she had experienced, the bladder research that was “done to death.” In this case, the participants realized the program worked and that it worked well. It offered services that were not offered anywhere else, and dealt with the feeling that everyone had – of being sad, depressed and alone. The TPSG took all those feelings away, and for Stephanie, that was “huge.” Another “huge” impact for Stephanie was the information they gathered and the fact that her family physician trusted it.

The feeling of profound isolation had dominated Stephanie’s experience of SCI. She said that she felt like a “unicorn” after she left the rehabilitation hospital and came home to a rural area where she was the only woman with SCI, and the only younger woman using a wheelchair. She felt “very cut off from the world” as she was the only one facing certain issues. Nobody really understood her. Stephanie had been quite pessimistic. She had had a negative experience with research. Conversations from the teleconferences, and the resourcefulness and wisdom of the other participants echoed in her mind after the sessions. She reflected back on what she had heard and shared with others.

The discussions about the role of women with SCI in the society resonated with Stephanie, and had a great impact. She became aware that because women are a minority of those with SCI injuries, the research on SCI has neglected their needs. Stephanie believed that the needs of women with SCI were not only related to the physical impact of injury, with effects on such areas as physical mobility, pain, sexuality and reproductive health, but also to these women’s role in the society as mothers, daughters and wives. She has never found research that looks into the emotional aspects of SCI for women, and
how they go on to cope, post-injury in their traditional roles. While men usually return from rehabilitation to their mothers and wives and are looked after, women go home to take care of their children, parents and husbands. Stephanie felt strongly that there should be more research into emotional side of SCI and its impact on the role of women in the family, in order to understand the processes and find mechanisms to better support women with SCI.

Developing relationships with the group members was very important for Stephanie. She had a “warm” feeling that these were her true peers who were there for her, a feeling she did not normally have in her rural living situation. The group gave her a feeling of “a nice closeness,” which she had lacked for many years. Knowing that there were others in the same situation reduced her sense of loneliness and the panic she occasionally experienced.

Stephanie felt that the group “matched well.” The diversity of the group gave her an opportunity to draw “wisdom” from different participants. Stephanie saw it as an advantage that all the women were older than her, and took the opportunity to learn from their experiences and from strategies they used. She trusted their word as “They’ve come through the war out on the other side of it.” She learned from their experiences, and adjusted her behaviour to a certain extent based on what she learned.

In return, Stephanie felt that she could provide emotional support to the group and “cheer somebody’s day” with her comments. Humour was important to her, and she liked to “be remembered as the class clown.” She also gave reassurance to others.

Stephanie’s relationships with others, primarily with her family and her family physician were influenced by her participation in the program. She became more positive,
and that in turn influenced her family. Her husband noticed this positive change. She embraced a healthier lifestyle and that also had a positive impact on her family, who in turn started eating in a more healthy way. Doing good for her family made Stephanie feel good about herself.

Stephanie developed a partnership relationship with her family physician by explaining to him about the TPSG program, and by sharing with him information relevant to her health. The most important thing for her was that her family doctor “trusted” her and he “trusted” this program. He trusted it because he knew that it involved a group of women who were “concerned about their health” and who were trying to be “proactive.”

Stephanie was “thrilled” by the program, especially since its benefits came as a surprise to her. It helped her “quit the pessimistic side” of her a bit, as “not all things turn bad.” The program provided emotional support which Stephanie felt had been missing from the day she acquired the SCI. “The trauma and change that comes from an SCI is just phenomenal.” The “loneliness” and the “beaten-down feeling” were “always there” as a person moved from rehabilitation into the community. For Stephanie, the program changed these feelings. The program changed her “demeanor somewhat,” in part because the group provided emotional support and wisdom, but also because of the facilitator, who was very calming and supportive. Stephanie came away with a more positive outlook about life in general because this program worked, and worked well for her.

She became much more proactive in regard to her health. She changed her eating habits, lost 25 pounds, and ate a healthier diet following the advice of the guest nutritionist. Because she changed her own routine, her family also became a little healthier: they were all being proactive about their health. Changes in exercise and eating
habits, and being proactive about her health made Stephanie more positive and kept her feeling that way. She saw this as a life change for herself and for her family.

She was “smartened up” by being “proactive” in maintaining her own health, and preventing future problems. The program increased her awareness of which check-ups had to be done on a regular basis. Stephanie immediately acted upon this new information. She did three tests which ought to be done annually, but which she had never done before, and she was booked to do them again next year. Stephanie was committed to them “forever.” She trusted the word of other group members and trusted the word of guest speakers. She became more proactive about her health by engaging her family doctor. She felt that the new information she shared with her family physician gave him a sense of empowerment because he could finally help her.

Stephanie claimed that her disability is not the SCI. Rather, it is the pain that “conquers” her life every day. In the course of the program Stephanie accessed invaluable information about pain from other women. She also had an opportunity to listen to a pain specialist and have some personal time with her. The pain specialist worked with Stephanie, taking into consideration her dislike for medicines and the fact that she had to be alert all the time because of her children. Stephanie still did not feel completely better, but she noticed signs of improvement based on the specialist’s recommendations. She had tried many pain therapies and seen many specialists but it seemed to her that the new therapy was “hitting right to the area.”
[I was] on a positive outlook in that we may tweak this and get this right for me… It may never go away, but my goodness, when you’re in 100% pain, if they take 20% away from you, you’re laughing. That’s huge, that’s a big, big deal. So I got that from the girls and from our speaker both, the combination of things that I’ve been doing. (Stephanie, telephone interview, July 8, 2004)

Stephanie connected with a new friend from the group and reconnected with another woman she had met in hospital. She was committed to maintaining these relationships.

At the beginning of the program in the evaluation planning session, each participant was asked to identify her personal goals for, and expectations from, the program. Stephanie’s picture (Illustration 4) identified clearly her expectations: weight loss, improvement in pain management, knowledge, strength, improvement, compassion, understanding, hands-on knowledge, answers to questions, and opinions.

When juxtaposed with the description of her experience of the project and what she got out of it at the end of the project, for Stephanie the change was real. The goals outlined at the beginning of the program were achieved. She had made plans and already started their implementation.

Illustration 4. Stephanie’s Goals
Stephanie’s extremely positive experience of the program was marked by emotional support, and the quality and quantity of specific information relevant for SCI she received. Emotional support broke her “unicorn syndrome,” her profound sense of isolation and the loneliness she felt, as the only women with SCI in her rural community. Access to information about a number of long-standing health issues she was struggling with gave her more control over her own health. These resulted in remarkable changes in a number of areas: in her attitudes and outlook, in her health, through changes in her diet and exercise habits, and in preventative check-ups and new pain treatment. She felt that these were life-long changes.

The program positively affected Stephanie’s relations with her family and with their family physician. Information she shared with the family physician was empowering for him, as he finally was able to help her.

Her experience of the TPSG program was very positive, as it was the only research she had participated in that she benefited from. She was committed to sharing the positive results with all those who were alone and lonely in rural communities and who were not touched by a program like this.

4.5 Claire

4.5.1 Biographical Sketch of Claire

Claire is 46, and the mother of two grown sons. She has been living with SCI for 41 years. She is fairly independent in performing activities of daily living, but her abilities have significantly dwindled with her age. She relies heavily on her family, and
the support of her husband, who also has a disability. Currently, she does not have paid employment but is a full-time volunteer. She lives in a town of 14,000.

4.5.2 Textural-Structural Description of Claire’s Experience of the TPSG Program

Claire described her experience of the program as a “helpful learning process.” She learned from the professionals who were guest speakers and she learned from her peers. Professionals either gave her detailed information that she did not know, or confirmed things she had suspected but did not have any expert advice on.

The quality of learning I was getting from the speakers and from the other women. And what an amazing group of women. For me, it just thrilled me no end to realize the caliber of women I was talking to, on personal, professional and experience levels. And so that kept me wanting to be connected to that… A very enriching experience of learning and growing and connecting to talented people living under great challenges. (Claire, telephone interview, July 10, 2004)

Through interactions with professionals and peers, Claire established professional, informational, emotional, psychological and peer connections that were vital for her.

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)

She felt that the learning that happened in the group indirectly impacted the communities in which the women live.
[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)

Satisfaction about the program for Claire came from the opportunity to “contribute to other women with SCI” her “little bits of information.” However, some of her questions about spirituality remained mostly unaddressed. Her concerns about her relationship with her severely disabled husband and how to balance life better with two disabilities in the house were also untouched because the family situations of other participants were not similar that way. However, connecting with Rose, who was a marriage counselor, opened a door for Claire to get help and advice.

Claire was concerned about the telephone and how effective it would be for the support group. She saw relying on the telephone only as the weakness of the program, since there are many other possibilities for communication using computers. Using other technologies would add flexibility to the program and make it even easier to schedule.

Claire had a very busy schedule and it was difficult for her to fit the TPSG into her life. Missing some of the sessions was a cause of frustration for her. She thought that having a teleconference once a month was perfect, twice a month was good, but hard to schedule, and more than that would be erratic and very difficult to schedule; however, less than once a month would not be enough to maintain the connection. She emphasized the role of the facilitator in helping her maintain the connection with the group by sending e-mails or notes from the sessions, or phoning to follow up.
But I think our facilitator did a lot of work of pre-planning, preparing, follow-up and things like that, that enabled the whole process to go many times smoother than I ever expected it would. (Claire, telephone interview, July 10, 2004)

Participation in the planning of the program, including monitoring and evaluation, was important for her, as she found it helpful to understand “where we were we trying to go and what we were trying to do.” It was “really nice to have been consulted” and asked for “ideas and recommendations.”

I just felt it was important to participate in seeing how you were going to try and achieve these things because as a participant in the conference it was great, but to actually be able to participate even indirectly in how the whole project from the first person’s concept of it, their viewpoint of trying to collect the data, to show how the data was collected, but what the data is, and how to analyze it, that was kind of exciting for me to see that come about. So I appreciated it. I felt that was important. (Claire, telephone interview, July 10, 2004)

Every time she was asked to use the participatory development tools Claire reacted differently. On the first occasion she was very enthusiastic, while on subsequent occasions she had more difficulties articulating and putting down her thoughts and emotions.

Though she had to cut out some activities from her life, Claire maintained engagement in this program because it was very important for her. She was sad that the program was over, but very happy that she had participated in it.

Claire was very aware that she had a different experience of SCI from other members of the group. A strong sense of difference made her feel nervous in the initial group interactions, as she was not sure that her contribution would be valuable.
I felt it’d been so long since my injury and I had such a different experience than those who had a direct, recent trauma as adults. Our experience levels would be so different that it wouldn’t help them to have me in the group. So that was my nervousness, what could I say or anything that they would feel comfortable listening to. Because my experience would be so different. (Claire, telephone interview, July 10, 2004)

Her comfort level in the interactions with the group members grew as she got to know them better and realized that she could contribute some of her experience. She described her role in the group as an “irritant” and a “Miss-Know-It-All, all of the time.” She thought that she did not get to say, as often as she really wanted to, how much she appreciated the women and how she did understand them, and feel for the situations they were facing. While listening to others, she realized that she has a lot in common with them and that her life experience is “universal”. She realized that her community work and experience working with other people with SCI could generate helpful information for others in the group, despite their different experiences of SCI.

Claire’s relationship to other group members was characterized by ambiguity. Sometimes she felt connected and understood. On the other occasions she was not able to connect because of her different experience of SCI. The program’s reliance on telephone and her inability to see the faces of other women made it even harder to connect.

I didn’t feel sometimes that I was connected or could relate some of my experience in this area. But that was okay. I think I was there also to learn of other people’s experience in other areas, so some of that came true, that I didn’t feel some levels of connection, but other levels of connection were very real and very helpful. (Claire, telephone interview, July 10, 2004)
This ambiguity in her relations to others was a cause of Claire’s occasional frustration with the program. Claire sometimes got impatient and frustrated with herself, and with the group, because of the way they were trying to communicate. While listening to other experiences she felt “very self-righteous” because she already had dealt with them and had a “grip on that.”

These frustrating moments made her draw back and look at what made her frustrated. As a result of this reflection, she learned to be more patient, more understanding, more empathetic, more appreciative that people were at “a different level of experience,” and aware that she had to be respectful of that. Learning to appreciate and accept differences better, recognizing the universality of own experience and knowing the uniqueness of the other members played an important role in Claire’s participation in the program. She felt that it was important for her to have the regular connection with these women she respected and admired. She felt that she did not have many occasions in her life to meet such a group of individuals. Although she had known many people with SCI, over many years, only a very small group had really “taken charge of their lives and pursued their goals and things they wanted to do” the way this group of women did. She got to know the other women in the group very well, better than she had experienced in any of the peer support programs she participated in.

Remaining in contact with the with women from the group was very important for Claire. Knowing that they were “out there” was a great support for her, even though she did not always feel she could learn from them. The fact that she knew other women struggling with the same issues every day made Claire feel more comfortable about how she approached her own life. Admiration and respect for these very different women who
had shared openly and generously the details of their lives helped her recognize and appreciate people with SCI in a different way. When it came to relationships with peers, the group deepened her ability “to be empathetic, and understanding others in the same boat,” and helped her become more respectful of others.

The program was yet another item in Claire’s tight schedule, but it taught her “a bit more balancing skills.” Claire felt that she had succeeded in reaching balance and reducing demands on her time. She was not sure if the group had helped her to develop that, or if she had been ready to do that on her own, but this was one of the initial concerns that Claire wanted the program to help her address.

She refined her peer support skills and reaffirmed her lifetime commitment to be “an encouragement and a support for people with disabilities in my community.” The program gave her “another level of understanding and knowledge to share with other people in my community” in her volunteer peer support work. It also gave her ideas that she can share about SCI. The program had “an indirect impact” on her community, as she spoke about it with her family doctor and members of the boards with whom she volunteered. They all thought that it was “fantastic.”

I learned better ways of expressing and saying things that I didn’t know how to put into words, but it was being said around me and I was going, yes, yes, that’s it, that’s it. (Claire, telephone interview, July 10, 2004)

She appreciated a lot the speaker with SCI who encouraged them to be “practical and easy” on themselves. This affirmed Claire’s own philosophy. Claire learned from her how to convey this message clearly, and thus improved her communication skills.
Structures of Claire’s experience of the program are linked to her distinctive experience of SCI, and the learning process that marked her participation in the program. Awareness of her difference hindered her ability to connect at all times with the group members. However, it also taught her to be more understanding, more appreciative and more respectful of difference. She also recognized that her own experience is universal, and that she shares many things in common with this group. This revelation made her feel much better, and more comfortable with the way she had lived, because she knew that they were others out there who were “in the same boat.”

Claire learned to be more understanding, empathetic and respectful of others. She also learned how better to communicate with others, and she knew this would help her in her peer-support, volunteer work. At the personal level she learned how better to balance her personal and volunteer life.

Some of Claire’s needs remained unmet by the program. Although she enjoyed her participation in the program very much, she expected more in the area of spirituality and family relations, in particular relations with her disabled husband.

She appreciated the opportunity to participate in the planning of the program. She had different responses to the participatory development tools every time she used them over the course of the program, responses ranging from enthusiasm, to inability to fully express herself.
4.6 Anne

4.6.1 Biographical Sketch of Anne

Anne is 43. Five years ago she acquired an SCI which initially left her paralyzed but later on she recovered her mobility. Now she is fully mobile and independent but suffering from excruciating pain, her “invisible” disability. She works in customer support in a big discount store. She lives on her own in a town of 100,000 inhabitants.

4.6.2 Textural-Structural Description of Anne’s Experience of the TPSG Program

The TPSG program for Anne was an opportunity to learn a lot from women with SCI and from the guest speakers. Both group members and guest speakers provided her with a useful and helpful “wealth of information” on living and coping with SCI. The program was flexible enough for her to skip the sessions with guest speakers who were not relevant for her. The topic on pain was most useful, as pain was her biggest problem. The following is a description of the group by Anne:

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)

Anne received a lot of information on how to deal with the emotional side of SCI. The program provided a safe environment for the group members to open up and “speak their minds,” something they did not get very often. This helped Anne with the changes that SCI has brought to her life – from being fully active to feeling unable to do things
and “feeling sorry” for herself. The group gave her the strength and optimism to deal with her challenges, knowing that she was not the only one struggling with them on a daily basis.

“I just have realized that we all have our daily struggles and we have to rise above it. There’s other people who are in my position in the group and, I think, just knowing that there’s other people out there that have problems like this is something that helps, you’re not alone. (Anne, telephone interview, July 14, 2004)

She did not have anyone to discuss her disability with. Her family and friends did not “really understand” her. She believed that the program gave everyone an opportunity to “get a lot off their chest.” The feeling of being understood by others who related to her problems was a “really, really big wonderful thing” she got out of the program.

The group met on a regular basis. She felt that the program team was open to suggestions, “all open ears,” and she could express her ideas. Anne pointed out the facilitator as a big strength of the program.

“...She just totally rules. I find her just so wonderful. Everything she said, the way she heard everyone. Like she didn’t just listen, she did so much more. She listened as well, to every little word. She’s really good at listening. And because I even heard her pick things out that people said, and she would turn that around and come back about five minutes later and bring it up again but in a humourous way, and it made that person feel, almost want to laugh about it. And it was just a very genuine and refreshing, just her whole way of interpreting what people had to say… she really puts her heart into it. You can tell. And that really impressed me. I think she’s just a wonderful facilitator. (Anne, telephone interview, July 14, 2004)

She liked the participatory development tools because they got her “mind working” and they were fun. They were also another way of “expressing yourself, who
you were and the points you wanted to make.” However, she was disappointed a bit with her lack of creativity when using these tools. The program was helpful as it answered questions, provided different perspectives and advice how women could make things better for themselves.

Anne’s participation in the program was determined by her perception of herself as being different. She knew that it was hard for other people to understand her disability. Because she was mobile and her disability was very different from the disabilities of other group members, she had difficulties relating to the group. However, many women in the group suffered from pain, and she knew exactly how they felt. She was not sure that she was the “right person to be in the group.” Although she benefited from the program, she felt that the group could have helped someone else more, someone who had more in common with the rest of the participants. Anne was also concerned that she could not be able to make contribution to the group because her different experience would not be relevant for others. She was somewhat frustrated at the beginning, when she questioned whether there was someone else who would better fit the group.

She was going through difficult time before she joined a group. The combination of physical pain and emotional distress was hard on her.

I would get emotional and upset and just think that I’m not… the person I used to be, and … who’s going to be happy with me when I can’t clean their house, and are they going to want to have to take care of me down the road… It wasn’t a terrible depression or it wasn’t even that bad, but it got to a point where I let myself… well you have to let yourself feel sorry for yourself. (Anne, telephone interview, July 14, 2004)
Through participation in the group teleconferences she realized that those feelings should not overcome her. She learned not to be “hard on herself” – not “feeling negative about everything.”

There’s a couple of women that are so positive in that group. Not just a couple but a few. And then there’s ones who aren’t so positive. So I think that that was a really good thing for the people who aren’t so positive to see. And it really helped when you see someone who’s dealing with it and not just letting it bother them. (Anne, telephone interview, July 14, 2004)

The positive examples from group members helped Anne to deal with the negativity she was experiencing in herself. She considered herself a positive person overall, although she did not always feel like that. When other people told her that she was strong to have gone through her experiences, she was not confident in the truth of the statement because there were others who had been through much more. She did not feel as strong as other people thought she was.

During the peer support sessions Anne compared herself with other participants, both with those who were strong and had information to carry on, and with those who were struggling to get where they wanted to be. After comparing herself to others, she felt she was lucky. She felt good about taking the time out of her schedule and devoting it to the group, focusing on something other than herself, talking to the group members, supporting them and listening to them. The group also gave her

a sense of satisfaction, from being able to be there for others, and they were there for me. And a sense of participation… So that was a really good feeling. (Anne, telephone interview, July 14, 2004)
Anne could not contribute a lot to the group because she had a different experience from that of the other members. This was a bit difficult for her as she could not provide actual suggestions or advice. However, her limited role in the program was not, in the end, an obstacle.

She felt supported by those who were strong, who struggled every day, fought negative feelings, and stayed positive. But she also related well to those who were not always feeling “as confident with themselves” in the same way that she sometimes did. She respected the women in the group who dealt with so much more than she did, who were strong, had a voice, could speak out, and went out to help others.

Some of the women in the group were role models for Anne. When she was thinking about aging she wished to become like one of those women. She realized that in order to be where she wanted to be in ten years she had to act now. The group helped her realize that she had to set goals now, in order to feel good about herself in ten years. She wanted to be happy in the future. She admired those women and wanted to be like them, upbeat and positive, putting aside all negative things and moving forward.

Following the whole disposition of being strong… they set an example for others who are in their position. You had at least three or four women in the group that stood out in my eyes with regards to that, but, that helped me a lot. Even the ones that weren’t like that, they helped me too because I can relate to them and I know that they get that slumped feeling, as I’m sure even the ones who were strong had those feelings too. But somehow they know how to put them aside and do what they have to do. (Anne, telephone interview, July 14, 2004)

Anne realized that the first step in changing things in her life was obtaining information. The next step she identified was to focus her energies and be positive about
changes in her lifestyle. The group helped her with both provision of necessary information and being more positive.

At the time of the interview she had already started implementing some changes. Anne organized the information she got during the TPSG program into binders, and made them easily accessible allowing her to return to them for information to “help your get on with your day.” She had already changed her pain medication. She was going to go to physiotherapy again. She was planning to start an exercise program.

Learning about SCI and how it affected other people physically and emotionally made Anne change her attitude towards herself and avoid being “hard” on herself. Instead of being hard on herself, she focused on positive things. Learning from different people with different experiences gave her the “positive outlook” she needed. She also considered becoming actively involved in helping others who live with pain.

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It was very hard for Anne to connect with the other members of the group because she experienced different problems in her everyday life and her issues were related to invisibility of her disability, to social relationships and to living with chronic pain. Her primary concern was being different from the other women, and being in what she thought was a better position from the other women – she felt that she was taking a place from someone else who could have benefited much more. Although she felt that she could have benefited more from meeting with a group of women with similar problems to hers, Anne found the whole experience of participating in the program very satisfying. It allowed her to compare herself with others and gain a better understanding of other
people living with SCI. Although she felt that she could not offer the group a lot of information and advice she saw her contribution as being mostly “listening ears” and understanding.

Several women in the group were role models for Anne, and helped her embrace a more upbeat and positive outlook. She realized that in order to age gracefully with SCI, she had to take some action now. She focused on herself, and on being positive. She organized her SCI resources and changed her medication. She was about to start physiotherapy treatment again and was looking into ways to join a safe exercise program.

4.7 Jane

4.7.1 Biographical Sketch of Jane

Jane is 58 years old. In an accident involving a horse-and-carriage six years ago she acquired quadriplegia. With her high level of paralysis, she is dependent on the support she receives from her assistants and caregivers in performing activities of daily living. She took early retirement and lives with her husband, who also retired in order to care for her. They live in a small farming community of 1,800 in rural Ontario. She loves her horses and her cats as “cats are very sensitive to how I feel.”

4.7.2 Textural-Structural Description of Jane’s Experience of the TPSG Program

Jane was the oldest woman in the group and the only one with quadriplegia. The nature of her injury and the health problems she was facing made it very challenging for

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1 The interview with Jane was hard to schedule because of her health condition. Finally when I managed to schedule the interview, Jane was not feeling very well. Given her difficulties talking and her experience of the program I kept the interview short. This was the shortest interview and did not have the depth of other interviews; however it provided me with enough information to write a short description of her experience.
her to participate in the telephone sessions. She attended only nine teleconferences. In order to facilitate the process, when she was available and willing to participate in the group session she was called by the operator to join the teleconference (unlike other members who called in themselves). When she took part in conversations it was obvious that she had difficulties talking. It was tiring for her and left her short of breath.

She had unique and very different needs from the majority of the members in the group, who had paraplegia. She repeatedly pointed out two aspects that set her apart from the rest of the group. She stated several times that she “was older than others in the group,” and that she was the “only quad.” The inability of the group to support her and provide her with information characterized her experience of the program.

She felt that the telephone peer support program was a good idea but in order to support the needs of women with quadriplegia, it would have to include her peers and provide information relevant to their needs. Such a program would

… get a diverse group of quads of different ages... Getting more information about research and quads. (Jane, telephone interview, July 29, 2004)

Jane relied a lot on the internet to find more information about quadriplegia. For her, the internet was her “information tool.”

Internet is phenomenal. I check out about new things and get new updates. Computer is a real lifeline. (Jane, telephone interview, July 29, 2004)
Because Jane had different needs and such a different experience of SCI, she was not able to connect with the rest of the group and did not receive the support she needed. She felt that other members of the group simply could not, and did not understand her.

I am much older. I got a bit of pain advice but I did not get any support because they do not understand. I am a quad and I am older than others in the group. (Jane, telephone interview, July 29, 2004)

Her perception of herself in relation to the group and the program had all negative determinants including not belonging, not connecting, not being understood, not being supported. However, despite her isolation in the group, it felt “good” to participate in the sessions. She recognized that it was very useful for others.

It helped a lot others as they were discussing issues related to family… but I am much older. (Jane, telephone interview, July 29, 2004)

The other members of the group drew close to Jane at the very beginning when she expressed the frustration of having to direct others, in doing what she herself used to do. Jane stated: “No one can move faster than me sitting right here in my chair.” The group’s experience of the program was marked by the frustration of not being able to support all members, in particular, Jane, who presumably had the greatest need.

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Jane’s experience of the TPSG program was characterized by difference. She was not a peer in the true meaning of the word. She had a spinal cord injury that left her with quadriplegia and a whole set of different needs and different experiences of her disability.
Because of that, she could not connect with others in the group. She felt that she could not be understood, as the group members could not relate to her experiences. Peer support was not provided because the group did not share her concerns and problems. The guest speakers and a vast majority of the topics were not relevant to her experience.

She did not benefit from the program in the way others did. With the exception of just feeling “good” about it because it helped others, and because of the potential of such a program to be used in support groups for persons with quadriplegia, the program did not have any relevance for Jane.
CHAPTER 5
RESULTS: COMPOSITE DESCRIPTION

The seven women with SCI who took part in the program contributed the narratives of their experiences. Their common denominator was a spinal cord injury, but they brought to the program a wide range of experiences.

This chapter presents a composite description of the meanings and essences of the experience for the group as a whole. They are presented as a series of themes organized according to several universal structures: space (which is in this case the TPSG program itself); relation to self; relation to others; and causality reported by the participants, in which they linked the different levels of change with the program (Moustakas, 1994). Although in this chapter there are several themes under separate headings, themes are deeply contextual and linked to the women’s individual experiences, their interactions, and the program as a whole.

This chapter ends with a general statement of the structure of the experience of the TPSG program, in which it moves from the individual descriptions of what it meant for each participant, to a general sense of what it means for someone to experience a facilitated telephone peer support program, a program which combines peer support sessions with expert speakers for women with spinal cord injury.

5.1 Dominant Themes

Seventeen themes emerged as the core themes of the experience. The themes are grouped into four universal structures as a way of presenting the group results in a clearer
and more organized way including: space, relation to self, relation to others, and causality. Each of the four universal structures include a number of themes:

A. **Space:** Telephone Peer Support Group Program; Emotional Support; Learning; Participation in Decision Making; Facilitator; Telephone and Participatory Development Tools – Pencil-and-Paper Tasks;

B. **Relation to Self:** Isolation and Loneliness; The Physical Aspects of Spinal Cord Injury; Self-Confidence; The Traditional Role of Women; Being Different;

C. **Relation to Others:** Support, Care, Compassion and Belonging; Exchange of Information and Knowledge; Comparison and Validation; Improving Relations with Family, Professionals, Community

D. **Causality:** Change: Attitudes and Knowledge; Behaviours.

5.1.1 **Space: Telephone Peer Support Group Program**

Participants experienced the TPSG program as a space where emotional support was available and where they could learn from peers and experts. They commented on the factors that facilitated these two processes, including participation in decision-making, the contribution of the facilitator, the use of the telephone, and the use of participatory development tools.

5.1.1.1 **Emotional Support**

Participants felt that the project provided them with rounded emotional support. For Rose it manifested itself as true peer support, exchange and sharing. Lydia experienced the program as a space to vent and laugh with peers. For all participants the
key to the emotional support was real understanding. Debbie gave an example of real understanding:

And so when I say I’m having a bad day and, you know, this, this, and this went wrong, they really don’t understand, but when you say that to somebody that is experiencing either the same things or has experienced it, you know they can commiserate with you. (Debbie, telephone interview, July 7, 2004)

Stephanie defined ‘understanding’ in a similar way. For her it was important that other participants really understood her

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)

Understanding was crucial for Claire and Anne as well, but they felt that their different experience of SCI may not be relevant for the group and did not give them the sense of “real understanding.” Jane2, the only person with quadriplegia, felt she could not receive the emotional support, as the other participants did not really understand her situation. However, she felt good about participating as it was helpful to the other participants.

5.1.1.2 Learning

Participants perceived the program as a space for learning from guest lecturers and peers. Rose learned a lot about herself by engaging with peers and listening to them. Lydia found out relevant information from guest lecturers, but she was able to “get a lot

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2 Jane’s experience was very different. It is included only under “relevant themes.”
of knowledge from the other girls.” She was amazed “how knowledgeable they were.” 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.”

Stephanie’s learning was facilitated by the amount of specific information she received that was at her “fingertips” in the program. Clair described the program as a “helpful learning process” in which she was impressed by “the quality of learning I was getting from the speakers and from the other women. And what an amazing group of women.”

Although Anne did not share exactly the same experience of SCI as the other women, she experienced the program as an opportunity to learn and access a wealth of information useful for living and coping with SCI. In this program, Jane learned about the potential that telephone peer support groups have for persons with quadriplegia. The information in this particular program was not relevant to her, and learning in her case did not happen at any other level.

5.1.1.3 Participation in Decision Making

Participation in decision making was really important for the group members. Rose stated “To be able to say this works, this works well, this doesn’t work well. I was really happy to have that opportunity.” Lydia appreciated having an opportunity to participate in the planning and evaluation, but generally she was satisfied with the direction of the program and did not have much to add. 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.” For Claire, participation in planning helped her understand the process of “where we were trying to go and what we were trying to do.” Anne and Jane joined the group later and did not take part in all planning sessions. For Anne, it did not really matter because generally she did not like to take part in planning exercises.

5.1.1.4 Facilitator

All participants agreed that the facilitator had a key role in ensuring that the program was implemented smoothly. Rose commented that the facilitator was responsive to the group’s needs. Debbie pointed out that the facilitator was good, and helped move discussions along nicely and easily. For Stephanie, the facilitator was also as source of information from whom she learned. Claire acknowledged all the background work done by the facilitator, while Anne emphasized that the facilitator was a major strength of the project: “I found her just so wonderful. Everything she said, the way she heard everyone. Like she didn’t just listen, she did so much more.”

5.1.1.5 Telephone

There was general agreement among all participants that the telephone was a good way for the peer support group to communicate. Rose mentioned that the telephone was “a breeze” to use. Debbie emphasized that it was very accessible as “everybody has a telephone” and it is easy to use. The anonymity of the telephone made it easier for the women to open up. Claire and Lydia missed face-to-face interactions with peers, however. Claire felt that using other means of communication such as computers would
make it easier for women to stay connected between teleconferences. Jane saw the potential to connect with her true peers – other women with quadriplegia – by telephone.

### 5.1.1.6 Participatory Development Tools – Pencil-and-Paper Tasks

Participants considered the pencil-and-paper tasks as an invaluable contribution to the program, particularly in its introductory phase. Rose considered them useful and saw the potential for using them differently throughout the program to further stimulate the group. Debbie felt that the drawings helped her get to know the other women faster. Stephanie shared the same view: “[they are] invaluable that way, because otherwise I think it would’ve taken us much longer to warm up to each other.” Anne considered them very stimulating as they “do get your mind working.” These tools allowed participants to express themselves differently: “a way of expressing yourself and who you are and the points you want to make, so I mean that’s always good.” Although they enjoyed using the participatory development tools, all participants also shared feelings of apprehension and dislike for actually preparing the visuals.

### 5.1.2 Relation to Self

The women’s sense of themselves influenced the way they experienced the program. Themes underlying their relation to self were a sense of isolation and loneliness, their physical experience of disability, their self-confidence, the perception of themselves as being disabled while at the same time being expected to fulfill woman’s traditional roles, and their sense of being different.
5.1.2.1 Isolation and Loneliness

All the women shared feelings of isolation and loneliness. This was manifested as isolation from the community in which they lived, and distance from family and friends. Stephanie summarized the feeling of being isolated as a “unicorn” syndrome. This is the way she described feeling when she returned to her rural community where she was the only woman with SCI of that age using a wheelchair. Lydia, who was divorced with adult sons, and who lived on her own, felt lonely, since her family and friends did not live close to her. Debbie experienced a sense of isolation in not being really understood by her able-bodied friends.

5.1.2.2 The Physical Aspects of Spinal Cord Injury

The physical experience of SCI influenced many aspects of the women’s lives, as well as how they felt and thought about themselves. SCI robbed Rose of her identity, of her sense of who she once was. She defined her post-injury experience as a search for new identity, for a new self. The physical experience of SCI for a majority of the participants was marked by pain and health problems. For some participants, the pain and health problems were negatively impacting them to the extent that they could not participate in the activities of daily living. Stephanie described pain as her true disability. Rose was successful in managing her pain. Debbie’s health problems were taking her out of a normal daily routine for a week every month. Anne, who was now mobile and not visibly disabled, suffered from excruciating, disabling pain, which was the main consequence of the SCI.
5.1.2.3 Self-Confidence

How secure participants felt in their own abilities, qualities and actions played an important role in relation to self, as well as relation to others. There seemed to be a connection between the participants’ level of self-confidence and their perceived contribution to the group. The more confident women identified themselves as contributors, while the less confident defined themselves as listeners. Rose “was lucky enough to refer probably… almost every person who came to the group as a guest.” Claire called herself “Miss-Know-It-All,” while Stephanie was comfortable being remembered as “a class clown,” sharing her sense of humour with the group. Debbie thought of herself as an “outgoing” person with information to share about community resources. Lydia harbored some negative feelings about herself as “passive.” She always tried “to be perfect” but never was “good enough.” Although Anne did not have negative feelings about herself, she often questioned the validity of her judgments and actions in relation to the group.

5.1.2.4 The Traditional Role of Women

During the peer support sessions, participants explored the expectations of women with SCI to fulfill the primary-caregiver role that is prescribed by the society and reflected on how this role influenced their feelings and thoughts about themselves. Reflecting on these issues made Anne upset and left her feeling negative: “I am not the person I used to be… who’s going to be happy with me when I can’t clean their house, and, are they going to want to have to take care of me down the road.” Lydia tried to cope with the conflicting identities of being a care provider for her family and being a person
with a disability, by totally denying her disability. This was despite being visibly disabled
and requiring a wheelchair.

When I first came out of hospital, you had to be as normal as possible, the
housewife, the wife, mother. And, that’s the type of thing you have to do, and
don’t let anybody think that you’re disabled. (Lydia, telephone interview, July 5, 2004)

Stephanie contemplated the expectations of women, and the lack of any support
for women with SCI in fulfilling their expected role of primary caregiver in the family.
“We come home with all the trauma and the drudgery of SCI, and we go back to looking
after our children and our parents and our husbands.”

5.1.2.5 Being Different

The notion of a peer support group is based on the premise that participants share
experiences, abilities and interests. Feeling different from others in the group might
undermine participants’ ability to relate to, connect to, and understand their fellow
participants. Consequently, feeling different might undermine their ability to benefit from
the group experience.

In this group, four participants identified themselves as different from the others.
For some, that difference did not prevent them from connecting well with the group, for
Jane it was so big that she could not benefit from the program at all. Rose felt that her
“double identity” of a being a disabled women and a health professional set her apart
from the others in the group. “I’m part of this group because I need to be part of that
support group and that’s great for me. The other ear listens to the dynamics of the group.”
Although she had somewhat different perspectives from others in the group because of
her professional background, many similarities closely connected her with the rest of the group.

Having acquired her injury in childhood, Claire did not experience adult life without SCI, and she expressed her concern that she did not share the same experiences with the rest of the group, “Our experience levels would be so different that it wouldn’t help them to have me in the group.”

Anne had an SCI but she was fully mobile; therefore she did not share many of the problems experienced by women who were paralyzed. Anne was aware of her difference and of the extent of her ability to connect: “I am mobile… it made me feel, that I don’t quite connect, but in a certain way I do.” Jane was completely different from the rest of the group members: “There were no other quads in the group. And nobody older.”

5.1.3 Relation to Others

The TPSG program was based on the development of a supportive and safe environment for women with SCI to interact. This made relations to others within the peer support group a key structure of the experience of the program. In addition to relations with other members of the group, participants interacted with their families, health service providers, and community members. These relations were impacted by the program, and interactions with families, service providers and community members impacted the relations within the group.
5.1.3.1 Support, Care, Compassion and Belonging

The relation of group members to each other was characterized by mutual support. Rose described the group as “a great group that was very open and receptive and supportive of each other.” For Lydia caring and compassion were two important relations within the group:

Because a lot of the girls, well most of them care, all of them care, but have different depths of caring… Some of the girls are… very compassionate, very understanding…that’s what you don’t get in the outside world. (Lydia, telephone interview, July 5, 2004)

Debbie had a strong sense of belonging to the group that gave her a sense of “not [being] alone floundering away out there.” Although Claire had a different experience of the SCI than the other women she stated that the group “helped me to connect with those women who I could feel admiration and respect for.” Stephanie found “the closeness that you finally feel with somebody again.” It made her “feel good that you can actually get it off your chest once in a while and somebody really understood and cared.” Anne experienced difficulties connecting with the group and relating to their problems as she had a different experience of the SCI. However, she did relate to the others when they were talking about pain, “I can’t relate to a lot of their problems, but I think when it comes to it, a lot of them do have pain, and in that sense I know exactly how they feel.” Claire was another person who had a different experience of SCI, but the women’s openness and generosity in sharing their lives helped her understand, “recognize and appreciate, even those around me here who have SCI background that I hadn’t appreciated in the same way.”
5.1.3.2 Exchange of Information and Knowledge

Exchange of information, both giving and receiving it, was a rewarding experience for all the women who participated in the program. Rose felt

… lucky enough to share with these people some of the great experiences I’ve had, and I hope that that’s allowed them to re-engage in the system, see some positive in it, become less cynical, be willing to, stretch themselves, try these things, and make their lives better. (Rose, telephone interview, July 1, 2004)

For Anne it “was really satisfying to be able to listen, because … I’m the type of person who helps people that way.” Lydia also liked “to listen rather than say a lot… so by sitting and listening I sort of got everybody’s opinions.” She also felt good about sharing “little snippets of opinion and information,” as she thought “that it was worth helping somebody.” Debbie had “a little bit of knowledge when it comes to, where to go for some things and I think that helped.” 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.” Obtaining useful information from peers was very natural for Stephanie, even when she was not looking for a specific answer: “a problem came out and another one had, ‘oh I had that happen and this is what I did,’ you would even pick up a solution that way.”

5.1.3.3 Comparison and Validation

The group provided opportunities for comparison and validation. Comparison caused negative feelings for some; for others it was a motivator. When Rose compared herself with others she learned “to be really very thankful and very grateful for what I
have.” Anne’s comparison with others confirmed her sense of being different but it also
gave her motivation and role models for being as strong and positive as the women in the
group who “set an example for others who are in their position.” Comparison with others
made Lydia feel “inadequate,” “useless” and “negligent” about herself. The group also
provided validation for its members for their feelings and actions. Debbie stated that “the
group has validated that I can feel this way and not feel bad about it.”

5.1.3.4 Improving Relations with Family, Professionals, Community

Participants felt that their relations to family, health care providers and
community members were developing along with their relations to their peers. Stephanie
a felt positive impact on her family, as they all started eating a “little bit healthier” as a
consequence of the program. She was also aware that the new information and
knowledge had allowed her to have different relations with her primary-care physician,
who, in her view, became more empowered “So he felt a little bit empowered as well,
that he can write that in the chart and say, okay, that’s doable, I can, I’ll do that for you,
sure.” Debbie summarized these changed relations with her health care providers as being
a partner in her own health: “Now I have some participation in my own health.” Prior to
the program, she felt like a passive and powerless recipient of health services.

5.1.4 Causality: Change

All participants attributed directly a certain level of perceived change in their lives
to participation in the program. They reported transformations which ranged from
increased awareness and knowledge about health and well-being, to new attitudes about
self, to modified behaviours and action. This variation in reported changes further
demonstrates the uniqueness of the experience of each participant.

5.1.4.1 Attitudes and Knowledge

The most obvious transformation reported by a majority of participants was the
change of attitudes towards themselves and life in general. Lydia felt that she remained as
lonely as she was before the program, but the experiences of other women and advice
from the guest speakers provided her with information and 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.”

Rose stated that the group had helped her find a new identity by learning from
other women how to fill the “void” created by the SCI, “It’s moved me to a final place I
need to be in order to move ahead.” She changed her attitude towards herself as she
“learned to be more forgiving, less critical of myself. More accepting, more content…
thankful.” Claire became “more comfortable about how I approach my life.” She felt
quite positive about herself even when she joined the teleconference but 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.”
Stephanie got “a whole positive look all the way around, too.” She felt “more positive,
things have changed.” Claire and Debbie felt that the program had also increased their
knowledge about peer support and improved their ability to use those skills in their
volunteer work.
5.1.4.2 Behaviours

Increased awareness, new knowledge and changed attitudes were the participants’ initial steps in making plans to implement change by adjusting their own behaviours. Participants reported changes that led to accepting a more balanced, proactive and healthy lifestyle.

For Claire, it meant learning to say “no” to adding new activities to her already-busy schedule, in order to balance her personal life and volunteering commitments. She felt that her “initial concerns were addressed.”

Anne’s commitment to become more proactive started by reorganizing the information and resources she received through the program. She started a new pain treatment: “I changed my medication, and I’m going to be taking physiotherapy again.”

Debbie had a major health problem that “nobody had the answer for me.” She resolved it through “a hint that came from a combination of speaking to the gynecologist and the girls when it came out.” She reported a major change “I’ve gone five months completely clear of no problems.” Debbie also received information that she had had problems finding before. The program made her feel “empowered” and “taking control” over her own health.

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.
She was also committed to maintaining the connections and friendships she had developed with the other women in the program.

Finding a new identity for Rose was a major result of the program as she finally found a way to bring together the two aspects of her identity: as a woman with SCI and as a health professional. The group helped her by improving her understanding of the lack of support and access to basic services for women with SCI, and focusing her attention on her experience of SCI and her professional abilities.

“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.” Rose launched the ProActive Spinal Network web-site, an online community for women with SCI. 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.

5.2 General Statement

Descriptions of experience in Chapter Four and so far in Chapter Five have been focused on the individual and group experiences of program participants. What follows is a general statement describing the structure of the experience of being a participant in the TPSG program.

5.2.1 Space: Telephone Peer Support Group Program

Participation in the TPSG provided emotional support in an environment which was safe for sharing, venting, laughing, connecting and exchanging. It was characterized by having a 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. Humour played a key role in achieving this understanding. Moments of doubt about whether they were right for the group, of feeling not connected, of feeling unable to relate were experienced by participants who were not true peers, because of the different nature of their injury or the length of time they had lived with the SCI.

The program was also a learning site with easy access to peers and experts who had up-to-date and relevant information and knowledge. The combination of peer support sessions and expert speakers worked well. To ensure the relevance of the program it was necessary to give participants decision-making power over topics and guest lecturers. By making them the decision makers, the program avoided ending up like some other research that did not mean anything and did not produce any results important for the participants. 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. Reliance on one method of communication did not hinder the development of close and open relationship among participants. A lack of visual contact in getting to know each other was overcome by the use of the participatory development tools which 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.
For some participants, the use of computer technologies were perceived as potentially enhancing the feeling of being connected and compensated for the lack of face-to-face contact. The regularity of meetings made it relatively easy for participants to fit them into their schedules, but this did not eliminate the challenge of irregular attendance.

5.2.2 Relation to Self

The women’s experience of the program was closely linked to their sense of themselves. Prior to joining the program, all the women felt profound isolation and loneliness. Some were struggling with the identity they had lost when they acquired the SCI, both personally and professionally. Although their experience of who they were depended on their life context of family and community, they became aware of the perceived conflicting identities of being a disabled woman with SCI, and the caretaker of the family. They remarked on the traditional role of woman in the society as a primary caregiver and questioned their own ability to fulfill that role without any support. The realization that some women with SCI have access neither 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, since it incapacitated them to the extent that they could not participate in the activities of daily living. 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 quadriplegia), 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 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 own experience of pain, or the daily challenges of living with SCI and this recognition allowed them to truly connect with, and relate to, other members of the group. The woman with the peer-professional identity in a way contributed most to the group, since she was functioning on two levels: as a peer (from her own experience) and as a professional (from her training in being sensitive to the group dynamic). The woman who had quadriplegia and was older than the others did not have the feeling of being connected to, supported by, and understood by the group.

There seemed to be links between self-confidence and the role each participant played in the program. The more confident women identified themselves as contributors of information and advice, while those who lacked self-confidence described themselves as “listeners.” They processed interactions with other group members in different ways ranging from empowerment, feeling good and being focused on the positive side of self, to negative feelings about themselves, describing themselves as being “inadequate,” “never good enough,” “useless” and “passive.”
5.2.3 Relation to Others

Participants’ relations to others reflected the multiplicity of other people with whom they interacted. These multiple others included the other participants in the group, as well as their own families, their health professionals, community members and other disabled people.

Relationships among the group members were based on a sense of belonging, relating, connecting, 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 perception of being different did not overpower the feeling of closeness for any of the women, except the one with quadriplegia. Diversity within the group contributed to more dynamic interactions, improved understanding and appreciation of difference.

Interactions within the group allowed participants to share their positive and negative experiences, to listen to others and be heard by others. It also gave them 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 adjust their behaviour 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. Learning from peers came in a natural way through discussions, even at times when they were not directly seeking answers to specific questions. Some group members had more information to share while others felt more comfortable being listeners, being more on the receiving end. All felt satisfaction from their interactions with other
participants regardless of whether they contributed information, experience, a joke, or off
ered compassionate ears and emotional support. They were aware that some information shared might not be correct or applicable and that potentially it could be harmful. Therefore, information exchanged in the group needed to be validated with professionals as well.

Access to professionals who were guest speakers in the program created learning opportunities as well as the possibility for participants to check information received from peers. Guest speakers gave information that are not easily available for women with SCI, on the latest developments in health research and services. Group interactions and access to expert speakers had an impact in the form of improved relations with family, health care providers, other peers and community members. These relations were characterized by 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. Family physicians serve a wide number of people with diverse health issues, and do not necessarily have a background in serving people with SCI. In this case of this study, the health care providers also work outside large cities, thus having no access to SCI treatment and rehabilitation centers with the information and other resources these centers can offer. 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.
5.2.4 Causality: Change

A majority of participants acknowledged some changes in their lives and attributed them to their participation in the TPSG program. The essence of the participants’ experiences of the program was linked to the transformations they underwent. Participants reported more positive attitudes about themselves and about life in general as one of the more important changes they noticed. Learning from peers and experts was translated into changes in the ways participants related to themselves and to others. Each participant, having a unique experience both of disability and of the program, reported a different level of achieved change. The changes reported by participants were attitudinal and behavioural.

Participants noticed attitudinal changes and generalized these to an overall feeling of being more positive about, and more comfortable with, themselves. They found new identities which embraced both new and old selves. Some participants learned about health practices to be followed in order to maintain good health. They 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. This, in turn, had the potential of proving useful for volunteering in other peer support programs.

For some participants, their experience of learning in the group and changes in their knowledge not only brought awareness of what they should do, but also reinforced their commitment to plan and implement changes in their lifestyle that they perceived to be important for improving health and well-being. These included organizing information.
gathered during the program, planning physiotherapy sessions, planning an exercise program and annual check-ups with family physicians and other specialists. For others it meant taking control over their own health, being more comfortable with themselves, and striking a balance between personal time and volunteering.

Feeling empowered, some participants soon changed their behaviours and started implementing plans, which, in turn, reaped results. They became more proactive about their health. Several participants changed their pain medication based on the advice of a guest lecturer who was a pain expert. Another participant reported weight loss and better dietary habits for herself and her family. She also completed annual preventative check-ups and booked them for the subsequent year. One participant who was motivated by the lack of information and access to basic services for women with SCI, and empowered by the support and encouragement from other members, launched a web site, an on-line community for women with SCI called ProActive Spinal Network.
CHAPTER 6
DISCUSSION AND CONCLUSIONS

In this final chapter, I shall discuss the findings of this study in relation to the other findings from the literature. I shall look into two main processes of support and learning and compare them with those reported by other researchers. I shall also discuss the participatory approach used in the program.

Also in this final chapter I shall take the opportunity to reflect on the overall study and its limitations, analyze the implications of this study for research and practice, and identify areas for future research. The chapter ends with a summary of the study and conclusions.

6.1 Discussion

This study represents an in-depth account of the experience of seven women with SCI who took part in a telephone peer support group program over 20 months. For participants the TPSG was a support and learning site in which they examined their relations to self and others. The TPSG helped them recognize changes that were necessary in their lives and encouraged them to make them. This resulted in feeling empowered, changing own attitudes and behaviours, and striking a balance in their lives.

Speaking from personal experiences of being disabled women, participants in the study echo the literature which indicates a general lack of research knowledge on unique issues affecting women with disabilities, in particular women with SCI. By emphasizing their overall satisfaction with the TPSG, these women expressed their deep dissatisfaction
with other research initiatives in which they had taken part but they considered neither useful nor beneficial for research participants. This highlights the need for establishing new partnerships which balance academic research agenda with research usefulness and action for participants (Schulz, Israel, Parker, Lockett, Hill & Willis, 2003).

Maintaining good health was a key concern for participants, as indicated in the literature on quality of life of persons with SCI (Manns & Chad, 2001; Noreau & Fougeryrollas, 2000). A majority of the group members had negative experiences of the health care system similar to those reported by Pentland (2002b) and Nosek et. al (2001). The TPSG created an opportunity for them to interact with health professionals in a safe environment of balanced power between professionals and users of services, resulting in re-engagement of TPSG participants with health system in an empowered way.

The findings of this study are discussed in relation to the relevant literature on peer support, transformative learning and participatory research. First, a comparison is made between the participants’ experiences of the support received in this program with some types of support described in the literature.

Second, three anticipated mediating processes within telephone support groups – identified in the literature as “social comparison,” “social exchange” and “social learning” – are compared to processes described by the participants in this group. The learning in the peer support group and changes reported by participants are examined through the lens of transformative learning.
6.1.1 Support

The levels of support expressed by participants were compared with those identified in the literature as emotional, affirmational and informational support (Stewart et al. 2001). It demonstrated that this program was successful in creating opportunity to for provision of all three types of support.

The telephone peer support program was a safe environment for participants to interact with peers who shared similar experiences. They were able to open up and pour out their thoughts and feelings. They listened to each other, related to each under and they were capable of fully understanding and helping each other with feelings of isolation, frustration and not being understood (Samuel et al., 2007).

Participants described teleconferences as opportunities to problem solve, gather positive energy, communicate effectively, break loneliness and feel compassion and friendship. That was reflected in the participants’ experience of the TPSG as a space where they received rounded emotional support, overcoming the neglect of women’s emotional needs reported in the literature (Samuel et al., 2007). It was also a space in which individuals shaped and transformed their perceptions of self. They revealed that the program allowed them, as women with SCI, to get together, listen to each other and offer deep understanding and empathy, a description similar to what is reported in the literature as characteristics of the supportive environment (Dennis, 2003a).

Although participants emphasized the emotional aspect, benefits were multi-faceted in nature and touched on many different areas at once. The main themes which emerged in participants’ relations to each other were real understanding, belonging, connecting, compassion, care and motivation. The identified themes corroborate other
research findings, which claim that telephone peer support can meet the support needs of
consumers with multiple sclerosis and HIV/AIDS (Harris, 2000; Stewart et al., 2001a; 2001b).

Participants’ relations to others were characterized by the morale boosting and
e ncouragement they received from their peers during the teleconferences. The TPSG
program was also a space where they compared themselves to each other, and validated
each other’s opinions, experiences and actions. The literature reports that this type of
support, affirmational support, occurs in peer support groups (Dennis, 2003a; Stewart et
al., 2001a, 2001b).

Participants had increased access to knowledge and information from peers and
guest lecturers, which in turn gave them a sense of empowerment. The information
provided was up to date and highly relevant to their lives, unlike information provided in
rehabilitation centers. The latter was reported to be not always relevant or timely
(Boschen, Tonack & Gargaro, 2003). This confirmed the findings of other researchers,
who stated that support in peer groups was most often found in the form of informational
support (Dennis, 2003a; Stewart et al., 2001a; 2001b).

6.1.2 Mediating Processes

Three anticipated mediating processes within telephone support groups are
reported in the literature, namely social comparison, social exchange and social learning.
These categories describe the dynamic of this peer support group as well (Stewart et
al., 1998; 2001a; 2001b). Participants reported that the program gave them opportunities
to compare themselves with others and validate their own experiences, attitude and
actions. Comparisons happened in both directions: upward comparisons, with peers who were role models and who gave them optimism, motivation and something to strive for; and downward comparisons, to those who seemed worse-off than they were (Solomon, 2004).

The TPSG program was a place for women to exchange their experiences, information and expertise about living with SCI. This process of sharing and exchange was essential for learning, and resulted in a number of reported changes (Borkman & Shubert, 1995). Participants reported different levels of change, which they attributed to the TPSG program.

Learning was at the core of the structure of the experience of the TPSG program, as reported by participants. For the participants of the program, the learning process was translated into changes in the ways they perceived and thought about themselves, and what actions they took. Each participant, having a unique experience of disability and of the program, achieved a different level of change, including attitudinal and behavioural changes.

The learning experience of participants could be illuminated through a lens of a transformative learning process, since the changes they reported correspond to the stages of transformation as identified by Mezirow (2000). Participants had an opportunity 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 (Baumgartner, 2001; Mezirow & Associates, 2000).
It is important to note that the main topic of the learning process they identified was health. Therefore, reported transformations were primarily linked to participants’ health and well-being. This supports the findings reported in the literature. In these findings, health and well-being are seen as important factors in determining quality of life, and life satisfaction among persons with SCI (Manns & Chad, 2001; Noreau & Fougeyrollas, 2000).

A majority of participants achieved a certain level of transformation, illustrating that the program had a significant impact on participants’ perception, attitudes and behaviours, similar to the changes reported in the literature (Harris, 2000; Schwartz & Sendor, 1999). The support, knowledge and information they got in the program helped them to identify new roles and build competence and self-confidence to implement them. It would be important to investigate in the future how participants of this program go on to reintegrate their new roles and perspectives into their everyday lives; however, it is beyond the scope of this evaluation.

6.1.3 Participatory Approach

The complex health and social problems of the 21st century have brought increased attention to alternative research orientations which promote community partnership, action, and social change as integral parts of research (Minkler & Wallerstein, 2003). The participatory approach is the key feature of the TPSG.

Women with SCI who took part in the program highly valued the opportunity to make all decisions about its design, implementation and evaluation. Through the participatory process, they developed ownership over the program. They were in control
of the overall program direction, feeling that they could shape it to meet their needs in all phases. This process recognized and valued their priorities, which is one of key principles of the participatory approach (Israel, Schulz, Parker, Becker, Allen III & Guzman, 2003).

Collaboration between the program team and participants was greatly facilitated by an extremely skillful program coordinator/facilitator. She had exceptional organization and communication skills, understanding of the main issues concerning women with SCI, and respect for the preexisting skills, knowledge and experience of women with SCI. These facilitator’s skills have been recognized in the literature as essential in conducting participatory research (Stoecker, 2003).

Participatory development or visual tools were successfully used in this program to initiate discussions, explore other ways of expressions, and stimulate reflections. There is growing recognition of the role that different creative arts can play in helping participants identify their strengths and weaknesses, map resources and assets as well as to share their problems and concerns (Minkler & Hancock, 2003).

6.2 Limitations

Although all efforts were made to minimize methodological limitations in this study, a number of limitations have been identified in the area of recruitment, member checking, and peer debriefing.

This study used a sample of convenience as all participants in the study were self-selected participants in the TPSG program. They included women who met the inclusion criteria and who were recruited either from a previous study or through the Canadian Paraplegic Association. Although all participants experienced the phenomenon, and the
sample size was within the range recommended by Creswell (1998) for a phenomenological study, it would have been beneficial to use purposeful sampling, with better-defined inclusion criteria, particularly in terms of type of SCI and length of time since injury.

Another limitation was related to member checking, which was completed two times in the early phases of the research. The first member check was at the end of the data collection process and the second one immediately after the initial analysis. Member checks gave me an opportunity to seek feedback from participants on the initial thematic grouping. Due to time constraints, it was not possible to conduct member checks in the later stages of the analysis, when individual and group descriptions were developed.

The third limitation of this study is the fact that I was the sole researcher involved in all stages of the data analysis. I used a variety of methods to ensure trustworthiness of the study. However, the study would have been strengthened by the involvement of a research team which would have ensured verification of the findings.

6.3 **Implications for Research and Practice**

No literature was located pertaining to peer support programs for women with SCI. None of the articles on other peer support groups report on the importance of group membership as it is assumed that peers do share experiences, issues and abilities. The following discussion of the program is in relation to the diversity of needs among a minority group within the population with SCI.

Although all women who participated in this study had an SCI, the activity limitations resulting from their injuries were very different. The program appears to have
resulted in remarkable changes in the lives of some participants. However, some women did not receive the same amount of support from the group, mainly because they could not completely relate to the issues and challenges shared by the other participants.

Three members of the group expressed their concerns about being different. One person, who was ambulatory, could not relate to many of the problems discussed. She also felt that she was not the most appropriate participant and that someone else would have benefited more from this program. The second person had lived almost all her life with SCI and had a different experience of disability. She also found it difficult to connect without face-to-face contact. However, both women successfully connected with the group at some levels of shared experience. These women reached the expectations they had from the program and expressed their overall satisfaction with it. The third woman, who was paralyzed with quadriplegia, did not benefit from the program as she could not relate, could not connect and could not achieve the necessary level of understanding with other members of the group. In addition, she experienced difficulties participating in the program, thus raising the question of the appropriateness of the telephone for the delivery of peer support for persons with high levels of paralysis.

Taking into account the above findings, it is important to emphasize that the recruitment of the program participants is extremely significant for achieving the desired results for all group members. It is absolutely necessary for participants to be true peers in sense that they share experiences, abilities, issues and challenges. In this study, the type of SCI had an impact on the group dynamic; therefore, it is crucial for all participants to have a similar functional status, in order to make such a group effective. Different ages and length of time since injury, providing there are no major variances,
could enrich the group dynamic and be beneficial, especially for younger and less experienced individuals. This recruitment consideration 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 further explored. However, in light of the latest developments in computerized communication technology such as the voice-over-internet protocol, the focus of further research in this area should be on 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 of the research conducted and funded for the people who should be the ultimate beneficiaries of the research. This will render the findings more useful and applicable in improvement of their quality of life. This research and action program has set an example that one participant described as a unique experience that was relevant and useful and not like many other initiatives of which she has experienced over the 13 years she had been living with SCI. The relevance of this program to its participants was ensured by giving them decision-making power over the program design in all phases, including planning, implementation and evaluation.

The role of professional facilitator in the peer support group should be considered in the design of the program, in particular if the program involves the participation of guest experts. A good facilitator deals with the logistics, facilitates a smooth
implementation of the program, ensures that the group does no harm, monitors group dynamics and provides opportunities for all participants to contribute to the program.

Participatory development tools proved to be an invaluable instrument, that provided a visual component, facilitated introductions and helped participants get to know each other in the initial phases of the program. Although participants felt apprehension when using them initially, they appreciated having used them in the program.

6.4 Areas of Future Research

This phenomenological study is an attempt to illuminate the experiences of women with SCI who participated in the TPSG program, an area that has not been researched previously. It is an exploration of the potential of a facilitated telephone peer support program with input from guest experts. This study looked at the program’s usefulness from the participants’ perspective, in meeting emotional and informational needs of women with SCI, who represent an under-researched and under-serviced subgroup among the population with SCI.

As a follow-up to this study, it would be important to investigate how participants of this program reintegrated their new roles and perspectives into their everyday lives. In addition to this, there are three general directions for future research. This research would involve study in the following areas:

1. The effectiveness of the peer support programs on a larger population with SCI;
2. Gender differences in experiences of SCI; needs and coping strategies;
3. Outcomes of long-term TPSG programs on the health and well-being of persons living in remote and rural areas.

6.5 Summary and Conclusions

This study was born out of the Telephone Peer Support Program for Women with Spinal Cord Injury Living in Small Communities and Rural Areas in Ontario, funded by the Ontario Neurotrauma Foundation. It represents the final chapter in the evaluation process of this innovative and participatory program, which produced significant positive results for a majority of the women who took part in it. Following the completion of the program evaluation, which employed mixed methods, the phenomenological research method was selected to deepen the understanding of the experience of the TPSG program from the participants’ perspective. The seven women who took part in the program contributed their narratives to this study. Their experiences were described using the phenomenological approach according to Moustakas (1994).

Emotional support and learning were main structures of the experience, as reported by women. 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 true 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, where relations to others developed into the positive interactions of informed and empowered individuals.

Women with SCI attributed changes in their attitudes and behaviours 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, to the establishment of a web-site 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 enriching and life-changing experience, which has a huge potential for reaching isolated women with SCI scattered around the country. For service providers, the TPSG program was an opportunity to provide important support services to underserved populations by using cheap and accessible technology. Thus they were able to impact the quality of life, and the health and well-being of their service users. For participatory researchers it was a rewarding experience of the usefulness of participatory research, because immediate benefits were reported by satisfied research participants.
References


APPENDIX A
PROGRAM DESCRIPTION

Telephone Peer Support Group Program for Women with Spinal Cord Injuries
Living In Rural Areas and Small Communities in Ontario

The Telephone Peer Support Group Program for Women with Spinal Cord Injuries Living in Small Communities and Rural Areas in Ontario was a project funded by the Ontario Neurotrauma Foundation to establish a telephone peer support program for a group of seven women with SCI living outside of major urban areas who did not have access to face-to-face peer support groups. The main goal of the program was to develop innovative peer support services in collaboration with women with SCI. Thirty-five teleconferences and one face-to-face meeting were organized over a 20-month period. The main objectives of the program identified in the proposal were as follows (Pentland, Jalovcic, Gould, Walker, Minnes, Tremblay & Robarts, 2002a):

- To increase the availability and variety of peer support services by developing in collaboration with women with spinal cord injury a sustainable and cost-effective telephone peer support group program, primarily targeting women who live outside of major urban areas;
- To increase the capacity of program participants to develop and sustain similar telephone peer support group programs;
- To improve participants’ quality of life;
- To evaluate the program with participants and disseminate the results, and
To replicate the telephone peer support program for other persons with SCI who live in small and rural communities.

Program Participants

Originally it was envisaged that two groups of between five and seven women would be established. Women were recruited from the database of the previous research on women with SCI by Pentland et al. (2002b) and through the Canadian Paraplegic Association. The following were the inclusion criteria: (1) women with spinal cord injury, (2) 21 years of age or older, (3) living in the rural or small communities of Ontario, (4) functional status did not preclude participation, (5) access to a phone line.

Initially, one group of five members was established. After two meetings one member left the group due to deteriorating health. There were difficulties in recruiting enough members for the second group and five months into the program it was decided by the program team and participants to invite three new women with SCI to join the existing group. Six months from the initiation of the program, the group had seven members. All participants agreed to participate in all phases of the program by signing the information and consent letter cleared by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

All women had spinal cord injuries. Six of them had paraplegia and one had quadriplegia. Six women were paralysed and one woman was ambulatory. The average age of participants was 48.4, ranging from 43 to 58 years of age. A majority of participants acquired their SCI 5 to 14 years ago, with one participant living with SCI for 41 years. They defined their level of independence in performing daily activities from
fully independent (three participants), to independent with assistance (three participants), and one dependent on assistance. All participants except one stopped working outside the home after their injury, and one took early retirement. Four participants were married, two single and one divorced. The size of their communities was very different, ranging from 1,800 to 150,000 inhabitants.

Over the course of the program, participation in teleconferences varied from two to seven participants per session. The average number of participants in teleconferences was four. A group of peers who started the program at the same time, and who shared similar experiences and concerns were more regular participants in the program than those who joined the program at a later date or had different experiences of SCI.

**Program Phases**

The program was implemented in three phases: planning, implementation and evaluation. In the first phase of the program the women with SCI together with the program team identified their main issues and needs, set the priorities, decided on the implementation model and established the criteria for the program evaluation. In order to facilitate this process, different participatory development tools were used. Participatory development tools are described in more details in the Program Implementation section.

Over the course of the program, the facilitator made sure that participants had an opportunity to influence the program and make changes and adjustments if required. The program can be described as an iterative learning journey in which participants had the opportunity to design a program which would meet their needs, and a chance to take responsibility for that program.
Program Planning

In the first five months of the program, six planning teleconferences were held. One of these teleconferences was focused on the development of the evaluation framework for the program. Two additional planning teleconferences were scheduled in the months following: the first one was to introduce new members and the second one was to discuss the evaluation framework with the new members. This program utilized participatory planning as a way to ensure a central role for the program participants in the planning process. Nichols (2002) argues that a participatory approach helps to empower participants, teaches them decision-making, communication and research skills and introduces a collaborative services approach. Involvement of the evaluator and the participants in program planning provides an opportunity to integrate evaluation into the implementation and administration of the program (Nichols, 2002).

During the planning phase, participants identified learning as a main expectation and objective of the peer support group. They wanted to achieve it through: (1) peer support – sharing and learning from peers, giving and getting support, and (2) increasing knowledge and access to the latest resources (people, organizations, communities in the research and service sector) relevant for their health and well-being. Participants agreed on two types of teleconferences: (1) with expert speakers (topics and speakers were identified in the planning phase), and (2) peer support teleconferences. They decided that all teleconferences were to be facilitated by the program coordinator.
Program Implementation

Following the planning phase, in the next 15 months, 29 teleconferences were held. Out of the total number of teleconferences, 11 teleconferences were facilitated peer support sessions, 12 had guest speakers, two were additional planning sessions, two were evaluation teleconferences and two were final wrap-up teleconferences. The evaluation teleconferences were held seven months prior to the end of the project and at the end of the project. Following the final evaluation teleconference it was decided that the group would have one face-to-face meeting to wrap up the project and discuss the draft evaluation report.

In the implementation phase, the coordinator/facilitator was responsible for organization, communication and management of the teleconferences. She distributed an e-mail in advance reminding participants about the phone-in procedures and the previously-agreed time of the upcoming session. Pre-conference e-mails were used to share other relevant information about the upcoming sessions. Although e-mail was predominantly used as a means of communication, having access to e-mail was not a requirement for the program. Participants elected to be contacted by e-mail, supplemented by surface mail and telephone.

The participatory development tools in this program, also known as “pencil-and-paper tasks,” were used during the planning and evaluation sessions. Pencil-and-paper tasks included impact drawings/self-portrait, an exercise called “fish and rocks,” a sorting exercise, and community and home mapping. The following are illustrations of three participatory development tools used – the self-portrait, fish and rocks tools and community and home mapping. More detailed description is in Box 1.
Box 1. Taken from Participatory Development: Concepts, Tools and Application in PRA/PLA & PME Methods, Training Manual by Mosaic.net International

**Impact Drawings** … are a very visual and creative way to measure change. Drawings can be used for visioning, to describe a current situation or to measure change. Participants are asked to draw a self-portrait or an important event that had impact in their life.

**Fish and Rocks** … explore the fishes or enablers (assets, resources, strengths) and rocks or obstacles faced in reaching a goal or result. By using fish and rocks participants can explore facilitators and obstacles in reaching goals or results at the personal, system and community levels. A river should be drawn on two pieces of flipchart, with one end obviously opening to a lake where the goal or result is posted. Participants are asked to define, indicate and place the fishes (assets, resources, strengths) and rocks (obstacles, weaknesses) related to achieving their goal or result. The larger rock represents the larger obstacle. Similarly, the larger fish the larger enabling resource or asset is.

**Community Mapping** … involves community members drawing maps of community structures, institutions, associations and resources. Mapping can provide insight into the interactions within community, available resources and access to them.

**Matrix** … is a table consisting of rows and columns which represent different characteristics or objects. A list of criteria or qualities are defined along one axis which then be ranked in relationship with the other axis.
Community Mapping

Instructions on how to complete them were also sent to the participants along with a self-addressed, return envelope several weeks before the teleconference. After completing the tasks, participants mailed the sheets back to the coordinator/facilitator. Prior to the scheduled teleconference the facilitator copied the contributions of all participants and distributed them to the group in packages mailed to their home addresses in time for the teleconference. This meant that all participants had copies of all materials.

At the agreed time, participants called in by using the toll-free number and entered the code assigned to the program. Teleconferences lasted up to two hours. The facilitator took notes and distributed them to the participants by e-mail. In the one case where dialling the phone was a barrier, the participant received a dial-out from the teleconferencing company.

*Peer Support Teleconferences*

Each support group teleconference started with a brief check-in. During the planning and at the evaluation teleconferences, the facilitator introduced the goal of the
teleconference and asked participants to comment on their pencil-and-paper tasks. Pencil-and-paper tasks were used to generate potential topics for discussion and as a starting point for exploration and discussion. Participants were encouraged to freely discuss any topics they considered important.

During the implementation phase, pencil-and-paper tasks were not used. The peer support teleconferences started with a check-in. A topic would naturally evolve from conversation and would be discussed in detail. Usually, during each support group session in addition to the SCI-related issues, the facilitator and participants dealt with program logistics such as scheduling, upcoming lecturers, preparing the list of questions for a specific lecturer, etc. The format would be somewhat free-flowing, so that logistical tasks undertaken by the group would sometimes provide the occasion for discussing more personal issues.

Discussion topics ranged widely, including everything from practical matters such as accessibility and equipment, to profound questions of relationships with spouse and children, and the effects of the women’s injuries on their self-esteem and self-image. At times, the discussion would take the form of support for one another’s feelings. At other times, the approach would be one of problem-solving or information sharing. As the group dynamic developed, it became easier and easier to move between these two modes of discussion. The following is a list of some of the topics which were covered:

- Accessibility and both physical and attitudinal barriers;
- Equipment and home renovations, and the best use of insurance funds;
- Relationships with people in positions of power and influence: health care professionals, insurance companies, and other funding and support bodies;
- Staffing – attendants and caregivers. How to find and direct home help;
- Experiences in initial hospitalization and rehabilitation. The women frequently discussed the lack of understanding for their particular needs as women, and the lack of psychosocial support they had experienced immediately after their injuries. The women offered each other support in recovering from the lingering pain of these early experiences, and often expressed the need to reach out to women who have been recently injured, so that their own negative experiences would not be repeated in future generations of women.
- All of the above issues were interwoven with the issue of advocacy.
- The need for information was an important theme. This gave rise to inviting a number of guest lecturers to attend the teleconference.
- Relationships with spouse, ex-spouse and children were frequently discussed. Parenting with a disability was a recurring theme.
- Time-management and self-care came up often in the groups. The need for self-care is evident, but it is difficult for women to fit it in to their busy lives, especially if they are trying to maintain families.
- The discussions about self-care led to exploration of much deeper issues, such as beliefs that the women might hold about themselves, and their expectations of themselves. The women challenged each other’s negative judgements such as “I’m lazy” – suggesting another perspective such as: “I’m overwhelmed with so much to do.”
- Exercise, motivation and weight control also came into this discussion.
Many meetings came back to the questions of: what really are the needs of women with SCI and how can these needs be met? The women in this group were concerned, not only for themselves but for other women with disabilities in general, and with SCI in particular. Discussion about personal issues often broadened out to include brainstorming about how to fill these needs.

**Teleconferences with Guest Lecturers**

Guest lecturers were identified during the support group teleconferences, mainly by the program participants. The program coordinator was responsible for contacting the identified lecturers, scheduling their teleconferences and communicating to them the participants’ list of questions and concerns. Participants had usually checked in earlier for a short briefing before the session with a guest lecturer started. Lecturers had one to two hours to discuss the topic of their expertise with the participants and answer their questions. Following each session with guest lecturers, participants had between 15 and 30 minutes to debrief and discuss the information they had received during the session. If guest lecturers agreed, the session was taped and distributed to participants who requested the tape. The program coordinator was also responsible for distribution of tapes and any other materials provided by guest lecturers.

There were 12 sessions with nine experts out of which six were physicians, one psychologist/nurse educator, one dietician and one physiotherapist from Canada and United States. Table 1 provides a summary of professions, topics and locations of experts who participated in the program.
Table 1. Guest Lecturers: Summary

<table>
<thead>
<tr>
<th>Guest Lecturers</th>
<th>Topic</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Physician, Physiatrist</td>
<td>Long term SCI, joints and arthritis</td>
<td>Ontario, Canada</td>
</tr>
<tr>
<td>2 Physician, Physiatrist</td>
<td>Recent developments in SCI research</td>
<td>Minnesota, USA</td>
</tr>
<tr>
<td>3 Physician, Gynaecologist</td>
<td>Menopause and women with SCI</td>
<td>Ontario, Canada</td>
</tr>
<tr>
<td>4 Physician, Physiatrist</td>
<td>Maintaining health after SCI</td>
<td>Ontario, Canada</td>
</tr>
<tr>
<td>5 Physician, Pain Specialist</td>
<td>Managing pain</td>
<td>Ontario, Canada</td>
</tr>
<tr>
<td>6 Physician, Physiatrist</td>
<td>Latest developments in SCI research</td>
<td>Ontario, Canada</td>
</tr>
<tr>
<td>7 Physician, Physiatrist</td>
<td>Pro-active health care</td>
<td>Ontario, Canada</td>
</tr>
<tr>
<td>8 Exercise Physiologist, with SCI</td>
<td>Challenges and goals: living with SCI</td>
<td>Colorado, USA</td>
</tr>
<tr>
<td>9 Exercise Physiologist, with SCI</td>
<td>Mind-body-spirit health care</td>
<td>Colorado, USA</td>
</tr>
<tr>
<td>10 Exercise Physiologist, with SCI</td>
<td>Ideal scenes for personal health</td>
<td>Colorado, USA</td>
</tr>
<tr>
<td>11 Dietician</td>
<td>Nutrition and aging with SCI</td>
<td>Ontario, Canada</td>
</tr>
<tr>
<td>12 Physiotherapist</td>
<td>Physical fitness with SCI</td>
<td>Ontario, Canada</td>
</tr>
</tbody>
</table>

**Program Evaluation**

The evaluation process aimed to give participants an opportunity to evaluate the program as they had experienced it. The purpose of the evaluation was fourfold:

1. to monitor the program based on the criteria established by participants in the planning phase, to feed back the findings and improve the program on an ongoing basis;

2. to evaluate the telephone peer support group program in meeting participants’ expectations in the following areas:
   2a. receiving and giving peer support,
   2b. giving participants a chance to learn about the latest scientific developments which might impact their health and well-being, using criteria established by participants themselves;

3. to obtain participants’ perspectives on the program and allow them to make recommendations on the direction of future programs;

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4. to assess the usefulness of the participatory development tools.

The logic model was developed to graphically present the logical relationship between the activities and results (Figure 1). The model was developed and revised during the evaluation planning sessions in which participants clarified their expectations, goals and results. The participants identified learning as a core process in achieving the results as well as the defining feature and driving force of all program activities.

Figure 1: Logic Model for TPSG (Telephone Peer Support Group) Program

<table>
<thead>
<tr>
<th>Activities</th>
<th>Outputs/Immediate Results</th>
<th>Outcomes/Medium-term Results</th>
<th>Impact Long-term Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>LEARNING</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participatory process, planning, implementation, evaluation</td>
<td>Participants’ needs identified, feedback used to adjust program</td>
<td>Empowered to act and demand action</td>
<td>Improved quality of life: Pro-active, healthy lifestyle choices</td>
</tr>
<tr>
<td>Peer support teleconferences</td>
<td>Emotional, informational and affirmational support</td>
<td>Positive attitude and motivation</td>
<td>Improved capacity to sustain similar programs: Getting organized for peer support</td>
</tr>
<tr>
<td>Guest lecturers teleconferences</td>
<td>Access to research info, specialist advice and latest knowledge</td>
<td>Know-how to maintain health and well-being</td>
<td></td>
</tr>
</tbody>
</table>

The participatory character of this program, the lack of published literature in this area and the diverse characteristics of the participants all guided the selection of methods
for the evaluation. Qualitative and participatory methods were selected in order to gain a better understanding of the women’s experiences and obtain their view on the effectiveness of the program, and the usefulness of the participatory approach itself.

The seven participants were able to offer sufficient information for a rich description of their experiences. This made this group suitable for a qualitative study. Another reason for the selection of qualitative methods was that these methods are complementary to the use of the participatory approach used at all stages of the program’s development.

In addition, participants suggested using simple questionnaires to capture the changes that occurred over time. They also wished to ask for the opinions of the guest lecturers on their experiences. During the evaluation planning sessions, participants and the evaluator developed the evaluation framework to be used to assess the program. The evaluation had the following components:

- Self-administered questionnaire, to monitor individual changes (beginning, mid-term and end of the program),
- A mid-term evaluation focus group,
- A final evaluation focus group,
- Individual interviews with participants at the end of the program,
- Guest lecturer’s feedback form.

The evaluator introduced the program evaluation to participants at one of the initial planning meetings. In a letter sent prior to the meeting the reasons for the evaluation were explained, and participants were asked to think about what they wanted
to get out of the program in the long run. Participatory development tools were used to obtain more information about their expectations of the program. The last teleconference of the planning phase was fully devoted to the development of the evaluation framework.

Participants, guest lecturers and the program team participated in the evaluation of the program format. Table 2 represents the summary of the expected results and the basic evaluation framework as agreed upon by the program participants.

Table 2. Evaluation Matrix

<table>
<thead>
<tr>
<th>RESULT</th>
<th>SOURCE</th>
<th>METHOD</th>
<th>FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Peer support</strong></td>
<td>Participants</td>
<td>Questionnaire</td>
<td>Beginning, Mid, Final</td>
</tr>
<tr>
<td>Emotional Support</td>
<td></td>
<td>Group teleconference, Individual interviews</td>
<td>Mid-term, Final</td>
</tr>
<tr>
<td>Affirmational Support</td>
<td></td>
<td>PD tools (impact drawings, maps, fish and rocks)</td>
<td>Final</td>
</tr>
<tr>
<td>Informational Support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Information and Knowledge</strong></td>
<td>Participants</td>
<td>Questionnaire, Group teleconference, Individual interviews</td>
<td>Beginning, Mid, Final</td>
</tr>
<tr>
<td>- experience of guest</td>
<td>Guest</td>
<td>Questionnaire or a short interview</td>
<td>After participation</td>
</tr>
<tr>
<td>speakers</td>
<td>Speakers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- participatory tools</td>
<td>Participants</td>
<td>Group teleconference, Individual interviews</td>
<td>Mid-term, Final</td>
</tr>
<tr>
<td></td>
<td>Facilitators</td>
<td>Diary, individual interview, notes</td>
<td>Final</td>
</tr>
</tbody>
</table>

In total, four evaluation teleconferences were conducted, two during the planning phase, one mid-term evaluation teleconference, and one final evaluation teleconference. Following the final evaluation teleconference, in-depth individual interviews were conducted with the seven participants and the facilitator. Qualitative analysis of transcripts of the interviews and teleconferences was used to develop the categories and themes.
A number of techniques were employed to ensure the trustworthiness of the evaluation: triangulation, member checks and saturation (DePoy and Gitlin, 1998). Multiple sources and data-collecting methods were used, including focus groups, interviews, drawings/pictures/other visuals, feedback forms – self-administered questionnaires, program documents and facilitator’s diary. They ensured multiple and rich descriptions of the program dynamics and processes. Data was also collected from guest lecturers and the facilitator. Member checks were used throughout data collection, transcription and analysis. The collection of data continued until the point of saturation was reached. That is, when information gathered did not provide additional insight or new understanding.

In the Evaluation Report by Pentland, Jalovcic, Gould, Walker, Minnes, Tremblay & Robarts (2004) it is concluded that using telephone to provide a peer support group program is an effective way of providing emotional, affirmational and informational support to isolated women with SCI living in small and rural communities. The program met the expectations of participants to learn through the exchange of experiences with peers and presentations by guest lecturers. The learning process that happened during the telephone peer support group sessions can be described as a transformative learning experience because it resulted in different levels of change in participants’ attitudes and behaviours.

The program failed to fully meet the needs of participants who had a different experience of SCI and did not share the same problems and issues with the majority of group members with paraplegia. Both an ambulatory participant and a participant paralyzed with quadriplegia had problems connecting with the group, as they did not
share the same experience. With the exception of pain management, both participants – in particular the participant with quadriplegia – found many topics discussed during the teleconferences irrelevant. While the type of SCI had an impact on the group dynamic, the different ages and length of time since injury actually enriched the group dynamic and were beneficial, especially for younger and less experienced individuals.

The participatory approach to planning, implementation and evaluation which had been employed in the program was a major contributing factor to the success of the program and to the high level of satisfaction with the program that participants expressed. Ensuring that participants had a voice and decision-making power in all program phases ensured that the program was responsive, and tailored to their needs. Participants developed a sense of ownership over the program.

Participants perceived the participatory development tools or paper-and-pencil tasks as a creative and appropriate way to provide visual connection throughout the program. They found them particularly useful at the beginning of the program, when they were used to introduce participants to each other. A majority of participants did not like doing them but truly enjoyed having the drawings in front of them during the teleconferences.

In the case of this pilot project, evaluation added to the time and costs, but these factors could be minimized in the future, and an extremely cost-effective, long-term program or series of programs could be established. If some variation of the teleconference project takes place in the future, a stepped-down program of ongoing support might be considered a second phase, after the initial two-year phase. The pure support calls could be conducted by the women themselves, at a very reasonable cost.
Based on the program, the following are some relevant recommendations:

- The costs of teleconferences were low and recalculated to current prices they would amount to $108.00 (CDN) per person per year, for twelve 90-minute calls at an average price of $0.10 per person per minute, or $9.00 for each person per 90-minute call.

- New technologies such as the voice-over-internet protocol offer cheaper or free teleconferencing services.

- The moderator was a critical component of the teleconferencing peer support calls and required specialized skills and knowledge related to group facilitation and SCI, as well as to participatory development methods. The moderator needs to be budgeted at roughly $50 per hour. In order to maintain regular communications with the participants, deal with ongoing issues, set up meetings and report on meetings, a moderator would need to be employed approximately one day a week, per group. Based on having one group, this would come to a yearly total of approximately $20,000.

- The experts in the pilot mentioned that they would like to be paid for their time, particularly if such a teleconference became an ongoing commitment. At a rate of $200/hr for 8, one-hour talks per year, this would come to a total of $1,600.

- The cost of supplies, postage, office and other sundry expenses may be budgeted at $500 per month for a yearly total of $6,000.

The cost effectiveness of this sort of health-education and social-support program is quickly evident, since (assuming 6 attendees) the annualized expense would be in the order of $28,000 or $4,600 per year, per person.
As a primary-health-care-enhancement, health-education and support program for women with SCI living long term in the community, this program has the possibility of preventing complications and related hospital visits, as well as making the best use of specialists’ time. When compared to in-patient services and more reactive methods of ongoing care, it would be especially cost effective.

The evaluation results were used to improve implementation of this program. They also guided the enhancement of an internet-based peer support program, which was a direct result of this initiative. Experiences of the program as well as evaluation findings and recommendations were shared with program participants and disseminated among various groups of consumers, practitioners and researchers in Canada and internationally.

**Post Scriptum**

1. The Ontario Neurotrauma Foundation funded the expansion of the peer support web-site which was developed on the participants’ initiative and with support from this Program.

2. In order to prepare an in-depth description of how the participants experienced this program, phenomenological analysis according to Moustakas (1994) was used to evaluate the program from an insider’s perspective, and describe the meanings of the participants’ experience in this program. The results of the phenomenological analysis are presented in the thesis.


Dear….  

You are invited to take part in a telephone peer support group for women with SCI.  

The project will take place over a total of two years, with the support group itself running for eight to twelve months within that period. The project will include twelve women living outside major urban areas in Ontario. The twelve women will be divided into two peer support groups of five or six members each. The telephone support group phone calls will not be recorded.  

This is a research project sponsored by the Ontario Neurotrauma Foundation and directed by Dr. Wendy Pentland from Queen’s University. Dr. Pentland also directed the recent study you participated in on women with SCI. 

Maria Gould, the Project Coordinator, will read through this consent form with you, describe the project in detail and answer any questions you might have.  

If you agree to participate, please mail back by November 8 the enclosed consent form in the stamped, self-addressed envelope we have provided. If you wish to ask any questions, please call Maria at (416) 243-3782 or toll free at 1-866-6786.  

IF THERE ARE ANY BARRIERS TO YOUR PARTICIPATION (if you need help with pencil-and-paper tasks, child or elder care, or anything else), PLEASE LET US KNOW, WE WILL FIND A WAY TO ACCOMMODATE YOU.  

With best wishes,  

Wendy Pentland, PhD  
Associate Professor  
School of Rehabilitation Therapy  
Faculty of Health Sciences  
Queen’s University
DETAILS OF THE STUDY

This project aims to collaborate with women with SCI living in small communities and rural area of Ontario. As a participant, you will develop and carry out a sustainable, cost-effective peer support program. You will also participate in evaluating the success of the program. You and your fellow participants may wish to develop and sustain your own telephone peer support program, and we hope that this pilot project will help you develop the skills to do that.

THE ROLE OF PARTICIPANTS

As a participant, you will take part in approximately 35 conference calls from the phone number(s) of your choice. The calls will last 45-90 minutes and will be funded by the project. There will be no cost to you. During the first five calls, you and the members of your group will work with Maria to plan and organize your support group.

Then, over the next ten months, you will participate in the telephone conference calls. These conference calls will be the peer support group. Maria will facilitate these calls. You and your group will decide how often you want to meet, and for how long. The teleconference calls will not be recorded.

At the end of the ten months, there will be approximately three teleconference calls with your group, in order to evaluate the process and get your feedback. In addition, you will be asked to complete your mailed questionnaires at the beginning and end of the project.

IF YOU NEED HELP WITH PENCIL-AND-PAPER TASKS, PLEASE LET US KNOW AND WE WILL ACCOMMODATE YOU.

SPECIAL RESEARCH TECHNIQUES

A key feature of this project is that the women will plan the support group process. The aim is to create a support group that will serve the needs of the participants rather than the ideas of an outsider.

This “Participatory Development” approach will involve about five teleconference planning meetings to find out the needs and concerns of the group members. The groups will also decide the format and structure which will suit them best. In this way, the group members will leave the study with the skills to continue amongst themselves, or to start another support group if they like.

RISKS AND BENEFITS TO YOU

The risks to you are that you may experience emotional stress during or after a teleconference call if a topic of issue comes up that is particularly difficult for you in your own life. One of the aims of the project is to give participants a chance to support each
other on some difficult issues. However, you do not have to share anything that you don’t want to.

After each teleconference, you are free to contact Project Coordinator, Maria Gould at (416) 243-3783 or toll free at 1-866-433-6786, or you can contact Principal Investigator Dr. Wendy Pentland (613) 533-6723 about your reactions and they will help you find resources or supports to help you.

The benefits to you are that you will have a chance to share and learn how other women are coping with Spinal Cord Injury and you will meet women with whom you can keep up the contact in the future, if you like. The aims of this project are to benefit you directly, but also to lead to a better understanding of how to best facilitate peer support programs in the future for the women with SCI.

CONFIDENTIALITY

All information given during the course of this project is strictly confidential and your anonymity will be protected at all times. You will be identified with your full name on mailed correspondence, first name in teleconference calls, and by ID number on all of our records.

Note that during the first call with members of your group, you will be introduced by your first name only. All members will know that each other has a spinal cord injury.

After that, it is always your choice as to what information you tell the group.

Data will be stored in locked files and will be available only to Dr. Pentland, the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board and the Health Protection Branch of Canada. You will not be identified on any publications or reports.

YOUR PARTICIPATION IN THIS STUDY IS VOLUNTARY. You may withdraw from the project at any time.

Liability: By signing this consent form, you do not waive your legal rights nor release the investigator(s) and sponsors from their legal and professional responsibilities.

Participant’s Statement and Signature Section: I have read and understand the consent form for this project. I have had the purposes, procedures and technical language on the project explained to me. I have given sufficient time to consider the above the information and to seek advice if I choose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information.

If at any time I have further questions, problems or adverse events, I can contact:
Dr. Wendy Pentland at 613-533-6723

or

Dr. Sandra Olney Director of the School of Rehabilitation Therapy and Associate
   Dean Faculty of Health Sciences at 513-533-6102

If I have questions regarding my rights as a research subject, I can contact

Dr. Albert Clark, Chair, Research and Ethics Board at 533-2975.

By signing this consent form, I am indicating that I agree to participate in this project.

__________________________  __________________________
Signature of Participant   Date

__________________________  __________________________
Signature of Witness   Date

STATEMENT OF INVESTIGATOR:

I, or the Project Coordinator, have carefully explained to the participant the nature of the above research project. I certify that, to the best of my knowledge, the participant understands clearly the nature of the project and the demands, benefits, and risks involved to participants in this project.

__________________________  __________________________
Signature of Principal Investigator   Date
APPENDIX C

ADDENDUM
CONSENT FORM

I, ___________________ (name of participant) have previously signed an Informed Consent for my participation in Telephone Peer Support Group Program for Women with Spinal Cord Injury, funded by Ontario Neurotaruma foundation and directed by Dr. Wendy Pentland.

I now understand that my participation in the evaluation process will involve completion of two questionnaires (at the beginning and at the end of the program), two telephone group evaluation meetings (mid-term and at the end of the program lasting between 1-2 hours), and one individual telephone interview (at the end of the program lasting between 1-2 hours). I understand that two group meetings and individual interviews will be tape recoded and notes will be taken. I may also take part in the process of analysis and interpretation of evaluation data, and making recommendations for the future programs.

All information obtained through interviews and recorded on audiotapes, notes and transcripts will be treated with confidentiality. Only researchers will have access to these documents. They will be stored in the locked files at Queen’s University Health Sciences in Kingston. My name will not be linked to any information and it will not appear in any report or published findings from this study.

Participation in the evaluation does not pose any additional risks or benefits to you, other than those identified in the consent form. Confidentiality and anonymity will be protected at all times. My participation in the evaluation is voluntary and I may withdraw from the project at any time.

I have read and understood the addendum to the consent form for this project. I have had the purposes, procedures and technical language of the project explained to me. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this addendum for my information.

If at any time I have further questions, problems or adverse events, I can contact Dr. Wendy Pentland at 613 533 6723 or Dr. Sandra Olney, Director of the School of Rehabilitation Therapy and Associate Dean Faculty of Health Sciences at 613 533 6102. If I have questions regarding my rights as a research subject I can contact Dr. Albert Clark, Chair, Research Ethics Board at 613 533 2975.

By signing this addendum to the consent form I am indicating that I agree to participate in the evaluation process.
Statement of Investigator:

I, or the Project Coordinator, have carefully explained to the participant the nature of the above research project. I certify that, to the best of my knowledge, the participant understands clearly the nature of the project and the demands, benefits, and risk related to the participation in this project.

Signature of Principal Investigator  Date
APPENDIX D
GUIDES FOR INTERVIEWS AND FOCUS GROUPS

Participants’ Interview Guide

Final Evaluation

This is only a general guide to conducting the individual interviews. Specific questions will be further refined and determined in collaboration with participants. The interview is designed to assist us with better understanding how you feel about the telephone peer support program after a year of its implementation. We have sent you the questions in advance to give you a chance to review the questions and think about your responses. Some of the questions are similar to those asked during the previous teleconferences. Our reason for asking these questions again is to find out if there are any changes in your perceptions and experiences of the program since the last time. Your responses will remain confidential.

1. How did it feel to participate in this program?
2. Compare the program to what you expected it to be.
   • Which of your concerns came true? Which did not?
   • What factors facilitated your participation?
   • What factors hindered your participation?
3. How satisfying has it been to participate in the program? Has it been frustrating?
4. How do you feel about the program right now?
5. How do you think the program affected you? Your family/community?
6. How did the program impact your everyday work/life?
7. What did you get out of this experience?
8. What have you learned in this program? From whom?

9. How did the group affect you?

10. How did you affect the group?

11. What specific issues were you able to discuss/resolve with peers?

12. What plans do you have to change your life or do things differently as a result of the program?

13. What are the strengths of this program?

14. What are its weaknesses?

15. How important was the opportunity to participate in the design, planning and evaluation of the program?

16. How did you feel about using ‘pencil-and-paper’ in different stages of the program?

17. How important is to have this type of service available for women living in rural and small communities?

18. Suppose you were asked by a funding agency if this type of program should be funded. What would you say? How would you support your argument with evidence (examples)?

Thank you very much for your helpful insights. Is there anything else you would like to share with us related to your experience in this program and how it affected you?
Focus Groups Questions - Guide

Mid-term Evaluation

(One telephone focus group of up to seven women)

This is only a general guide to conducting the focus group interviews. Specific questions will be further refined and determined in collaboration with participants.

1. How did you decide to participate in the program?
   • What was happening in your life that stimulated your decision to participate in the program?
   • What previous experience in peer support/phone-services have you had?

2. Now that you are a participant in this program, how do you feel about it? Describe your feelings about the program.
   • How do you feel about being part of the peer support group and sharing sensitive and personal information?

3. What about this program appeals to you?

4. Do you have any concerns or doubts about the program? If yes, what?

5. What have you learned so far through participation in this program? From whom?

6. How did the program affect you personally? Describe any changes that you have noticed which you attribute to this program.

7. What are the strengths of this program?

8. What are its weaknesses?

9. How could the program be improved? Who should do it?
10. Thank you very much for your helpful insights. Is there anything else you would like to share with us related to your experience in this program and how it affected you?
Focus Groups Questions - Guide

Final Evaluation

(One telephone focus group of up to seven women)

This is only a general guide to conducting the focus group interviews. Specific questions will be further refined and determined in collaboration with participants.

The interview is designed to assist us with better understanding how you feel about the telephone peer support program after a year of its implementation. We have sent you the questions in advance to give you a chance to review the questions and think about your responses. Your responses will remain confidential.

1. How satisfying has it been to participate in the program? Has it been frustrating?
   - What factors facilitated/hindered your participation?
2. What did you get out of this experience?
3. How did the program affect you personally? Describe any changes that you have noticed which you attribute to this program.
4. What have you learned through participation in this program? From whom?
5. What plans do you have to change your life or do things differently as a result of the program?
6. How important was the opportunity to participate in the design, planning and evaluation of the program?
7. What do you think about use of ‘pencil-and-paper’ tasks in different stages of the program implementation?
8. What are the strengths of this program?
9. What are its weaknesses?

10. Suppose you were asked by a funding agency if this type of program should be funded. What would you say? How would you support your argument with evidence (examples)?

11. Thank you very much for your helpful insights. Is there anything else you would like to share with us related to your experience in this program and how it affected you?
## APPENDIX E

### EXAMPLES OF AUDIT TRAIL

<table>
<thead>
<tr>
<th>1. Raw data</th>
<th>Handwritten notes made on margins – real understanding</th>
</tr>
</thead>
<tbody>
<tr>
<td>And, my husband commented on quite a few things on how positive I was about the conference and, he said the odd time, you know, gee, this must really help. And, you know, it does. It hugely does. I just had to be able to open up to somebody and have them really understand, not just kind of understand. (Stephanie, pg 4)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Data analysis and interpretation</th>
<th>Meaning units</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Meaning units (raw data)</td>
<td></td>
</tr>
<tr>
<td>I felt that I learned a lot from them as well as from the group discussions with the guest speakers and stuff. (A 1, p 1)</td>
<td></td>
</tr>
</tbody>
</table>

| b. Codes – Initial Coding in NVivo (excerpt) | |
| NVivo revision 1.3.146 Licensee: D Jalovcic |
| Project: Telephone Peer Support Group Program |
| Date: 12/24/2007 NODE LISTING |
| Nodes in Set: All Tree Nodes; Modified: 12/24/2007 - 6:48:35 PM; Number of Nodes: 101 |
| 1 (1) /Learning |
| 2 (1 1) /Learning/from peers |
| 3 (1 1 1) /Learning/from peers/dealing with emotional side |
| 4 (1 1 2) /Learning/from peers/dealing with health issues |
| 5 (1 2) /Learning/from guest lecturers |
| 6 (1 2 1) /Learning/from guest lecturers/negative feeling towards guest lecturer |
| 7 (1 2 2) /Learning/from guest lecturers/did not participate when not relevant |
| 8 (1 2 3) /Learning/from guest lecturers/positive |

| c. Selection from raw data and codes | |
| A very enriching experience of learning and growing and connecting to talented people living under great challenges. (C21, p7) |

| I learned a lot about my health. I learned a lot about future care, what to look for, we started even talking about nursing homes and stuff. So maybe we could start being proactive about having nursing homes that are geared more towards spinal cord injury and assisted living programs. (D 32, p7) |

| Emotionally this has been the biggest thing for me. (S 51, p11) |

| 1. Learning from Peers |
| 2. Learning from peers dealing with health issues |
| 3. Learning from peers dealing with emotional side |
### d. Comparison of findings among participants

<table>
<thead>
<tr>
<th>Rose</th>
<th>Lydia</th>
<th>Debbie</th>
<th>Stephanie</th>
<th>Claire</th>
<th>Anne</th>
<th>Jane</th>
</tr>
</thead>
<tbody>
<tr>
<td>True peer support</td>
<td>Able bodied care</td>
<td>Access to information</td>
<td>Phenomenal</td>
<td>Learning</td>
<td>Learning</td>
<td>Good program</td>
</tr>
<tr>
<td>Exchange</td>
<td>Understanding Vent</td>
<td>Relevant</td>
<td>Emotional</td>
<td>Access to info</td>
<td>Access to info</td>
<td>Not relevant</td>
</tr>
<tr>
<td>Sharing</td>
<td>Boost morale</td>
<td>Understanding Participation in design</td>
<td>Participation in design</td>
<td>Connections</td>
<td>Contributing info</td>
<td>Different needs</td>
</tr>
<tr>
<td>Vent</td>
<td>Humor</td>
<td>Understanding Participation in design</td>
<td>Understanding</td>
<td>Tel not very effective</td>
<td>Rely on other technology</td>
<td>Not alone</td>
</tr>
<tr>
<td>Understanding</td>
<td>Belonging</td>
<td>Tel easy access</td>
<td>Access to information at ‘fingertips’</td>
<td>PDT different reactions</td>
<td>PDT different reactions</td>
<td>Flexible</td>
</tr>
<tr>
<td>Humor</td>
<td>Access to information</td>
<td>PDT useful intro</td>
<td>Good facilitator</td>
<td>PDT</td>
<td>PDT stimulating</td>
<td>PDT</td>
</tr>
<tr>
<td>Good</td>
<td>Participation in design</td>
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<td>PDT stimulatin</td>
<td>intro</td>
<td>Scheduling a challenge</td>
<td>stimulating</td>
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<td>Did not like PDT</td>
<td>Access to information</td>
<td>Scheduling a challenge</td>
<td>Humor</td>
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<td>Irregular attendance</td>
<td>Irregular attendance</td>
<td>Irregular attendance</td>
<td>facilitator</td>
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<tr>
<td>in design</td>
<td>PTD</td>
<td>Good facilitator</td>
<td>Huge potential</td>
<td>Huge potential</td>
<td>Huge potential</td>
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<td>Participation in design</td>
<td>Participation in design</td>
<td>Participation in design</td>
<td></td>
</tr>
<tr>
<td>important</td>
<td>Did not like PDT</td>
<td>Different needs</td>
<td>Tel not very effective</td>
<td>Rely on other technology</td>
<td>Rely on other technology</td>
<td></td>
</tr>
<tr>
<td>Combination</td>
<td>PDT</td>
<td>Different needs</td>
<td>Rely on other technology</td>
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<td>Rely on other technology</td>
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<td>worked well</td>
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<td>Different needs</td>
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<td>Ownership</td>
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<td>Irregular</td>
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<td>Rely on other technology</td>
<td>Rely on other technology</td>
<td>Rely on other technology</td>
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</table>

3. Findings – phenomenological description
   
   a. Individual Textural-Structural Descriptions
   
   Included in the body of the thesis

b. Composite Textural-Structural Description

Other documents

1. Research project proposal

2. Research and evaluation design planning
   
   a. Minutes from the planning teleconferences

3. Implementation
   
   a. Notes from the teleconferences
   
   b. Attendance logs
   
   c. Memos

4. Instrument development
   
   a. Guide for interviews
<table>
<thead>
<tr>
<th>5. Analysis notes</th>
<th>6. Data summary and synthesis</th>
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</thead>
<tbody>
<tr>
<td>a. Field notes</td>
<td>a. Minutes from the face-to-face meeting</td>
</tr>
<tr>
<td>b. Progress updates</td>
<td>b. Evaluation Report</td>
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