



Health Recovery Social Networks: Exploring the experiences of participants in stroke recovery peer support groups

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-ABSTRACT-

This paper explores the experiences of participants in Stroke Recovery Canada®'s local peer support chapters throughout Canada. From a community perspective, these peer support groups create a social network founded on a health issue. Gathered through semi-structured interviews with a subset of peer support participants, this research offers an exploration of the social and health recovery developments that social networks can offer. Stroke Recovery Canada®, a program of March of Dimes Canada, is a non-profit, charitable, social economy organization and is based on a non-medical model. Through connecting stroke survivors with other survivors, the Stroke Recovery Canada® program aims to promote recovery and develop a support network for individuals who have survived a stroke.

Many questions direct this research. What models of sharing and learning do these community groups utilize? How do peer support groups affect the health recovery of participants (self-reported)? How does a social network affect an individual's learning about their health issue? Although this research is in its preliminary phase (n=9 interviews), the collection and analysis will be informed by peer support and related literature.



Background on Stroke Recovery Canada®

Stroke Recovery Canada® is a national program established to offer support and services to local and provincial stroke recovery groups and clubs across Canada. It is a program of March of Dimes Canada, which aims to maximize the independence, personal empowerment and community participation of people with physical disabilities. Although the charitable roots of March of Dimes date back to 1951 with a focus on polio vaccinations, the organization has evolved to provide a wide variety of programs and services to over 40,000 people annually (March of Dimes 2008).

In Canada there are estimated to be more than 300,000 people living with the effects of stroke. There are 50,000 strokes per year and with the post-stroke survival having risen 20% in the past ten years, there are more people living with stroke in the community. Furthermore as the population ages, the risk of stroke increases (Heart and Stroke Foundation 2009).

Stroke Recovery Canada® offers services across the country with a focus on peer support and a model of survivor driven community based support. The program provides information and awareness to stroke survivors, caregivers and healthcare professionals on how to both 'survive and thrive' after a stroke. Stroke Recovery Canada® also provides backing to vital peer support networks throughout Canada.

Stroke Recovery Canada® offers a variety of services that empower stroke survivors and their families to participate in their communities and to find support during the often challenging period of recovery. Some of these services include:

- Assistance to start a peer support group in their community (including coaching, manuals, business cards, website promotion, phone line, email, event insurance and much more)
- Monthly newsletters with suggestions for group activities
- Monthly conference calls to connect with survivors across Canada
- Annual leadership conference for survivors and caregivers
- Stroke Recovery Awareness Month (May) activities (this year's activity was a stroke survivor photo contest)
- The Phoenix bi-annual stroke recovery magazine



- Warmline (toll free number 1-888-540-6666 for information about stroke and stroke recovery)
- Stroke recovery research and advocacy
- Special programs/events: Conductive Education® (an innovative learning system based on principles of neuroplasticity that merges elements of education with rehabilitation), Walk 'n' Roll mall walk fundraiser, Stroke Survivor and Caregiver Retreat, Aphasia Camp, and more

Millions of dollars are raised annually to fund stroke prevention and research, but little support has been provided to assist stroke survivors and their families with stroke recovery. Through Stroke Recovery Canada®, we hope to fill this gap, and provide resources to stroke survivors and their families through new and existing groups across Canada. The mandate of Stroke Recovery Canada® is to raise awareness about the importance of community re-engagement for all stroke survivors.

Purpose of Research

The purpose of this research is to gather the experiences of stroke survivors who are participating in a stroke survivor support group for many reasons:

- To acknowledge the experiences of survivors after their stroke and highlight the role of peer support groups in the recovery process;
- To raise awareness of peer support groups and their value;
- To share stories with other survivors and the public;
- To expand stroke research beyond the realm of medical research;
- To enable March of Dimes Canada staff to gain insight into the experiences of survivors in peer support groups to inform future initiatives.

Research Design

This research is designed to provide survivors of stroke the opportunity to share their experiences of stroke recovery and to describe the role peer support has played in their post-stroke lives. Using semi-structured interviews, survivors offered roughly an hour of their time to review their stroke experience. The framework of the study and the interview questions were informed by stroke research as well as literature concerning social and peer support. Although the researcher based the interview on 15 predetermined questions, the semi-



structured format allowed for follow up on new themes the participant raised. Participants were provided information about the research project through their peer support groups (in meetings or through newsletters) and all participants volunteered their time. Each participant was able to choose to be anonymous or named within the reports. Currently, 9 interviews have taken place either by phone or in-person (depending on the comfort level of the participants). Some participants have aphasia which is a language disorder that can cause difficulty in using, understanding and producing language (Heart and Stroke Foundation 2005). We offered an aphasia supplement (pictures and simplified written questions to be used as aids) and we also offered to meet in person (face-to-face) upon request. After the initial interviews, we extracted the key topics raised in order to assess the emergence of general themes across interviews. We are hoping to expand the project to include several more survivors (n=30). With a larger number, we are hoping to be able to compare experiences between newly established groups and older ones as well as small versus larger groups and so forth.

Context for the Research

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In exploring the utility of peer support groups for stroke survivors, it is important to start with the literature available relating to stroke. However, it is also valuable to explore other complementary research concerning social support networks, self-help and groups brought together by a health concern.

There are a number of different beliefs about what is most important to recovery, ranging from medications, to physical rehabilitation and so forth, but community reintegration or social support may sometimes be overlooked. The 2009 *Getting on With the Rest of Your Life After Stroke* report produced by the Canadian Stroke Network explains that support is important for stroke survivors and wrote “Creative activities produce social bonding, help relieve stress and promote recovery,” (p.23). In a 2009 joint survey organized through March of Dimes Canada and the Heart and Stroke Foundation of Ontario, 100% of the 21 Ontario groups who responded indicate that their group shared information between the members and supported each other. Although peer support may take different forms (such as support groups, professionally led groups, peer coaches and so forth) they share themes of emphasizing what peers can offer to each other (such as their experiences and knowledge) (Heisler 2006). Thomasina Jo Borkman explains that “many self-helpers find



self-help/mutual aid organizations to be an arena where they are received as subjects, not objects, and where all facets of their selves can be revealed: where they are, indeed, whole persons,” (1999, p.25). Where people may not be able to find all of their strength from within, others can help to encourage and motivate them.

Wellness and social support are often linked. Janet E. Farmer et al. highlight key elements of previous social support research, such as a reported decrease in quality of life after persons lose friendships following a traumatic brain injury, social isolation often follows and their study emphasizes the importance of professionals remembering the relationship between quality of life and socializing (2003). However, because recovery from an illness can require a lot of support, it is often costly and not possible for professionals such as medical doctors to provide the support needed to facilitate a strong recovery (Colella and King 2004). By promoting peer support, people are able to find support in their recovery and have the added bonus of speaking with others who can empathize with their situation (Heisler 2006). Support is often linked with positive long term health and wellness (Hogan et al. 2002).

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People may seek peer support at different stages of their recovery and not all participants in support groups take the same approach. Thomasina Jo Borkman explains that participants in self-help groups can take an approach of “reactivity” where they feel as victims in their circumstance (often newcomers to the group) or alternatively, they might take an understanding and acceptance approach which Borkman describes as “self-determination” (often with persons who have been able to work through some of their challenges within the group) (1999). A 2004 study by J.B. Kingree and R. Barry Ruback illustrated that affiliation with a self-help group was correlated with persons being able to better accept their situation. A traumatic brain injury study by Mary R. Hibbard et al. showed that peer mentoring produced high ratings for empowerment. Peer support can help serve a crucial social need in peoples’ lives (2002).

-FINDINGS-

Overview of Participants

Ages range from 40 to 75 years of age with a mean age of 56. They face a number of different challenges due to their stroke such as mobility and balance



issues, physical challenges (often can only use 1 side of body well), language or swallowing problems, memory and mood challenges and so forth. However, 1 participant reports very minor deficits resulting from stroke due to receiving a clot busting drug (tPA) within the proper time after the stroke. Only 1 is working full-time and none have returned to the employment situation that they held prior to their stroke.

There are 7 different peer support groups represented in the 9 interviews, all of which are in Ontario. One participant started attending their peer support group just a couple months after their stroke, while others as late as 4 years after their stroke, although most commonly survivors joined their group approximately 1 year post-stroke (mode= 1 year after stroke). Participants' involvement in their group ranges from less than 1 year to more than 9 years and all but 1 are still participating with their group. The survivor no longer participating in the group treated the group as a transitional support structure for the time immediately following their stroke. There is an even split between 3 categories of involvement in their groups; 1) general member (who attends meetings and some events); 2) active member (who attends meeting, events and who sometimes helps out or volunteers with group projects) and 3) executive or board member (who take the lead or hold a title within their group). All participants mentioned having some other type of social support such as a family member or friend in addition to their peer support group. More than half are involved in some type of development program such as rehabilitation, exercise, or speech and half of these have been offered or organized through their peer support group.

Description of Groups

Peer support groups can take many different forms. For the seven groups represented in the interviews, six of the groups are led by stroke survivors, care providers (spouses or family members or survivors) or a combination of both. The remaining one is coordinated by a social worker. Most groups meet monthly although some meet more often for special programs such as exercise classes (weekly). All 7 groups represented indicate a very important social component of their group gatherings where survivors could meet with and learn from other survivors. Almost all groups indicated that having guest speakers or an educational component of the meetings was important. Most groups also included a time for discussion, sharing, recreational and fun



activities/games. Many survivors describe their group membership as diverse either in age, occupation prior to their stroke, mixed gender and so forth. There are 2 groups represented that are designed specifically for young stroke survivors (who had their stroke before 45 or 50 years of age).

Key Themes

The following themes were common to several or all of the participants. Overall, the 9 experiences expressed in the interviews shared many of the same themes. Other than those listed below, fear was emphasized as a great challenge in accepting stroke. Laughter and being positive were also commonly raised as key components of a successful recovery and of strong peer support groups.

Peer support groups helped survivors understand their stroke

Many participants indicated that at the time of their stroke and during their hospital stay, they did not feel they adequately understood their stroke or how they could cope with recovery. For a few, they were in a coma or faced challenges with aphasia (trouble with language), but none of the 9 participants indicated feeling their doctor or other hospital staff sufficiently answered their questions about their stroke.

“We don’t learn enough. Doctors never told me anything.”

–Lillian, 1.5 years post-stroke

“I wanted a place to learn more and educate myself more on stroke and how to cope with life.” –Richard, 2 years post-stroke

“I didn’t understand stroke until I went home and started seeing other stroke survivors.” –Tom, 7 years post-stroke

“When I first had the stroke I went to my family doctor 3-4 times a week thinking I would be having a stroke. I was always scared,” and indicated “the group helped me overcome my fear.” –Kelly, 4 years post-stroke



“When they [other survivors] talked about their experiences and how they coped...I learned tips on how to get on with it.” –Lena, 2.5 years post-stroke

Peer support groups helped survivors not feel alone or isolated

Almost all participants commented on the importance of connecting with other survivors. At least half of the survivors expressed gratitude to have received either a visit in the hospital or a phone call from a stroke survivor. They articulated that the isolation of their stroke seemed somewhat alleviated once they connected with others in a similar situation.

“You find you’re not alone. [The group] is an extended family who knows what you’re going through.” –Angela, 11 years post-stroke

“Just by going and listening to their [other survivors] stories...there is really something to that. Learning the stories of recovery ... helped me [learn] people can recover. It gave me hope where I thought through the years that you couldn’t recover.” –Irene, 5 years post-stroke

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“We’re not alone. Everybody else is the same as us. I’ve learned from coming [to the group] that there is life after stroke.” –Tom, 7 years post-stroke

Although many survivors experienced depression post-stroke, their support group played a role in overcoming depression

Only 1 participant did not report depression was a part of their stroke experience. Of those who experienced stroke, the majority expressed their support group played a significant role in overcoming depression.

“Being together with such a happy group who had disabilities too helped me keep my spirits up so I don’t let myself get down.” –Lena, 2.5 years post-stroke

“When I first came home from the hospital I wanted to go home, sit in a corner and cry.....now every month I have something to go to.” –Aryln, 7 years post-stroke



“I personally thought about suicide. It’s really scary. In forums they [survivors] all said we felt depressed...in the beginning it’s very normal. I’m not alone feeling that way.” – Angela, 11 years post-stroke

“They [the support group] helped a lot. I talked about depression and why I wanted to commit suicide and they were really supportive.” –Tom, 7 years post-stroke

Speaking to other survivors is different than speaking to other family or friends

All but 2 survivors reported that their experience speaking with other survivors was vastly different than speaking with their families. They felt survivors were more understanding and patient with them. Some expressed that they did not want to seem as though they were complaining so they avoided sharing their experience with family members.

“They [other survivors] speak to me and then they’ll listen. Some people would say ‘oh, I can’t be bothered’. They’re like friends because they’re always willing to help you” –Lillian, 1.5 years post stroke

“Other friends are like ‘we’re happy you’ve done this [recovery] but we don’t understand.’” –Angela, 11 years post-stroke

“[Talking to] people who have the same experience---it’s so much different.” –Lena, 2.5 years post-stroke

Improvement and recovery can occur over a longer period than expected

When participants left the hospital, many understood that whatever strides they were able to make in their recovery over the first year would be the end of their recovery. Many participants indicated that they still are making strides towards new recovery goals and seeing results.

“My doctor said ‘what you won’t get back in 1 year, you won’t get back’. I’m still finding improvements. I still can’t



do some things, but I got so much back I feel I have a lot to live for.” -Lena, 2.5 years post-stroke

“I still have progress now...I couldn’t lift my hand at all and now it’s higher than before.” –Aryln, 7 years post-stroke

Helping Others

Although many of the participants expressed gratefulness for the contributions their support group had brought to their lives and recovery, they also expressed that an important motivation for staying with their group is being able to give back and help others.

“[The group] gave me strength and I want to give it back. We’ve all been there, we all understand. We’re still going through it. We can talk, cry and laugh together---that’s what’s important about the group.” –Angela, 11 years post-stroke

“You share what you can do and maybe they [other survivors] can do it too. Mostly now it’s me helping [others].” –Arlyn, 7 years post-stroke

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What did these survivors want new survivors to know about stroke peer support groups?

“They can help you and be very helpful with resources.” – Kelly, 4 years post stroke

“Don’t be so fearful after you have [had your stroke]. I remember being afraid and that’s where the group helped.” - Irene, 5 years post-stroke

“I would encourage [new survivors] very much to join. It’s worth more than gold to get with [other survivors].” –Lena, 2.5 years post-stroke



Conclusion

Peer support has proved valuable in many health related populations and stroke is no different in this respect. Peer support can play a very important role in helping stroke survivors handle their stroke experience and move positively through recovery. Social networks are valuable to people in various realms and times of their life and perhaps even moreso when facing a dramatic change in lifestyle such as that brought on by a stroke. Stroke Recovery Canada® will continue to encourage stroke survivors to find a meaningful role in their communities through engaging in peer support groups. Future research will involve exploring the care provider's (spouses, family and so forth) perspective on peer support.

“The group is almost like my family. [After stroke] you lose friends that you’ve had for years. They drop out of sight...which is common I’ve learned. I guess they don’t understand. Now I’ve got a new family of friends I’m happy [with]. If it wasn’t for Stroke Recovery Canada®, I might not even be here today. I feed off it. It helps me keep going.” –
Tom, 7 years post-stroke

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