Research Article

Young Women Stroke Survivors and Their Desire for Peer Support

Sharon-Dale Stone

Department of Sociology, Lakehead University, 955 Oliver Road, Thunder Bay, ON, Canada P7B 5E1

Correspondence should be addressed to Sharon-Dale Stone; sstone@lakeheadu.ca

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The concerns of young stroke survivors are not well known. The aim of this paper is to draw on data from a larger study to show that young women who survived a hemorrhagic stroke desire access to peer support, but there is not widespread access to peer support. Open-ended interviews were conducted with an international sample of 28 women to learn about their poststroke experiences and were analyzed qualitatively for common issues and themes. A prominent theme across the interviews was the significance of age-similar peer support. Participants discussed feeling alone and misunderstood and wanting to have access to peer support. In conclusion, peer support may help to enhance psychological well-being, but the survivor’s own understanding of her peers must be centrally considered.

1. Introduction

Although stroke is more common in old age, it is not unusual for a young person (under age 65) to have a stroke. Estimates of stroke incidence according to age vary, but it appears that approximately 30% of strokes occur in people under the age of 65, and 3–4% occur in people aged 40 or younger [1]. For people aged 20–44, an American study found an incidence rate of 23 per 100,000 per year [2]. Regarding stroke in children, estimated incidence rates vary between 1.5 and 5.1 per 100,000 per year [3]. Young people appear more likely than old people to have a hemorrhagic stroke [2, 4]—typically (but not always) caused by a ruptured aneurysm or arteriovenous malformation (AVM); and survivors of hemorrhagic stroke are likely to be left with residual impairments that are not immediately obvious [5]. For example, cognitive impairments are commonly found as a long-term consequence of stroke at a young age, although this remains an understudied topic [6].

Young survivors of stroke not only contravene popular ideas about stroke as a disease of old age, but they must often negotiate a social world in which there is little understanding that not all impairments are visible. This situation can create significant psychological distress. Researchers in the UK, for example, found in focus groups with young stroke survivors that they “bemoaned the widespread lack of awareness of stroke in younger people, reflected in poor service provision and general ignorance about the impairments that stroke leaves behind, which are often invisible or not easily comprehensible” [7].

These concerns about lack of awareness about stroke under age 65 and the invisibility of stroke-related impairments were also discussed in this author’s [8, 9] previous research on women who survived hemorrhagic stroke between the ages of 8 and 49. The present paper discusses another theme to emerge from this research—the need for peer support for this population. The focus is on what they say about feeling alone and misunderstood and wanting to have access to peer support.

1.1. Peer Support and Women’s Psychological Well-Being: A Brief Review of Literature. A considerable body of literature suggests that a well-developed social support network can enhance health-related quality of life [10]. Research suggests, moreover, that social support networks play an especially important role in women’s lives [11]. For example, women tend to learn within the context of connections with others [12], and women are likely to rely upon nonfamilial support networks to discuss feelings about illness [13].
When dealing with a chronic health condition, however, a woman’s preexisting support network may not be adequate for helping her to cope and maintain a sense of psychological well-being. This is particularly the case when dealing with a condition that is potentially stigmatizing or poorly understood by the lay public. One study, for example, found that women with a chronic illness did not see their family or preillness friends as supportive but that friendships developed after diagnosis were “stronger and healthier,” and having a chronic illness led participants to reach out to similarly situated others to offer help, compassion, and empathy [14]. As well, studies of members of cancer support groups show that they find their peers to be more supportive than family and friends [15]. Regarding people with stroke, there is some evidence that peer support groups are useful for helping to come to terms with what happened and reducing a sense of isolation [16].

Studies of the use of peer support by women with breast cancer show that they find it beneficial to meet and talk to another breast cancer survivor, regardless of their marital status [17]. Marital status was also irrelevant in a study of women with multiple sclerosis [MS] who were trained to offer telephone peer support, where it was found that the women benefited greatly from helping others with MS [18].

Altogether, research shows that peer support is a unique type of social support that can help to enhance psychological well-being as women cope with illness, disease, or a stigmatizing health condition. In the literature, however, a discussion of peer support for young stroke survivors has yet to be developed. Indeed, there seems to be little recognition of a need for peer support on the part of young stroke survivors.

1.2. Availability of Peer Support for Young Stroke Survivors. In the U.K. the charity Different Strokes offers support to young stroke survivors by sponsoring numerous peer-led groups that meet in various locations throughout the UK, and there is an annual conference. Different Strokes also offers telephone peer support, newsletters, an interactive website, and a quarterly newsletter. As such, it offers resources that are unparalleled elsewhere in the English-speaking world.

In North America, several internet sites offer support to young stroke survivors. One site invites individuals to write a brief narrative for posting, and a content analysis of selected narratives posted there shows that both male and female survivors of an AVM hemorrhage are interested in sharing experiences with other survivors, although men are less likely than women to post a narrative [19]. Such sites can offer invaluable support to survivors [20], but are of no use to those who do not have ongoing access to the internet. As well, even those who visit these sites find that they would still like to meet their peers face-to-face. In North America, however, there are few peer support groups that meet face-to-face.

2. Methods and Data

The data are drawn from the author’s larger qualitative research project designed to gather women’s accounts about their experiences of surviving hemorrhagic stroke before the age of 50 and to learn what participants consider important for understanding their poststroke experiences. The research was approved by the Research Ethics Board of the author’s university and that of a participating hospital. Participants have consented to the use of their comments discussed in this paper.

A diverse sample was sought in order to examine the extent to which there were commonalities and differences across a number of variables. The aim was to recruit a sample reflecting diversity in terms of geographical location, socioeconomic status, race, ethnicity, age at stroke (but all were required to have experienced the stroke before age 50), and length of time since stroke (but all were required to have experienced the stroke at least two years prior to being interviewed, so that they would have had some time to adjust to what had happened). To this end, a purposive sample of 28 participants was recruited from Canada, the United States, Scotland, and England. Recruitment proceeded using a variety of strategies: a notice was posted both in a newsletter for young stroke survivors (published by Different Strokes) and on several internet support sites; women who had published accounts about aspects of their experiences were contacted; and physicians were asked for assistance with contacting patients. In the recruitment letter/notice, potential participants were told that the researcher was a survivor of a childhood stroke interested in learning about their poststroke experiences.

All but two of the resulting sample are Caucasian, as well, two self-identify as Jewish, three as of Italian origin, and one as Portuguese. At the time of the interview, all were from three to 33 years after stroke, so that each had learned to accommodate for residual impairments and could reflect upon poststroke experiences. Residual impairments varied but were primarily not visible to others—for example, hemiparesis or cognitive impairments such as aphasia. As well, almost all participants commented on easily becoming fatigued. As shown in Table 1, participants were between the ages of eight and 49 at the time of stroke and between the ages of 19 and 57 when interviewed. Twelve participants were married or partnered at the time of stroke and were with the same partner at time of interview. As well, 15 spontaneously indicated that they would like to have peer support, six discussed their experiences of attending a peer support group meeting, and seven did not discuss a need for peer support.

Data were gathered using unstructured, intensive interviews. The author traveled to conduct all interviews, which were either held in the participants’ homes or in three cases in a nearby restaurant. Interviews ranged from one to three hours in length, with most lasting one and a half hours, and all were tape-recorded for later verbatim transcription. Participants were asked to talk about whatever they considered important for understanding their poststroke experiences and were provided with little direction, although the author encouraged each participant to comment on certain common topics: experiences surrounding the actual event of stroke and recovery; experiences with the medical profession; being or not being recognized as disabled; self-image; relations with others; and perceptions of the significance of the stroke.
Table 1: Selected participant characteristics.

<table>
<thead>
<tr>
<th>Name/pseudonym*</th>
<th>Age at stroke</th>
<th>Age at interview</th>
<th>Intimate partner at stroke; and at interview</th>
<th>Indicated feeling alone and/or misunderstood</th>
<th>Indicated desire for peer support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barbara*</td>
<td>17</td>
<td>47</td>
<td>Lived with parents; married at interview</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Bonnie*</td>
<td>29</td>
<td>37</td>
<td>No partner; status unchanged</td>
<td>Yes</td>
<td>Yes and has attended group</td>
</tr>
<tr>
<td>Brenda</td>
<td>46</td>
<td>56</td>
<td>Married; status unchanged</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Chris</td>
<td>25</td>
<td>37</td>
<td>Partner; with new partner at interview</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Deirdre</td>
<td>8</td>
<td>19</td>
<td>Lived with parents; status unchanged</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Esther</td>
<td>24</td>
<td>43</td>
<td>Single; later married and divorced</td>
<td>No</td>
<td>Not discussed</td>
</tr>
<tr>
<td>Fernanda*</td>
<td>39</td>
<td>48</td>
<td>Divorced; status unchanged</td>
<td>No</td>
<td>Not discussed</td>
</tr>
<tr>
<td>Grace</td>
<td>35</td>
<td>41</td>
<td>Single; status unchanged</td>
<td>Yes</td>
<td>Yes and has attended group</td>
</tr>
<tr>
<td>Helen</td>
<td>32</td>
<td>40</td>
<td>Married; status unchanged</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Ida</td>
<td>38</td>
<td>45</td>
<td>Married; later separated</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Jackie</td>
<td>37</td>
<td>40</td>
<td>Married; status unchanged</td>
<td>Yes</td>
<td>Yes and has attended group</td>
</tr>
<tr>
<td>Jan</td>
<td>37</td>
<td>47</td>
<td>Married; status unchanged</td>
<td>Yes</td>
<td>Yes and has attended group</td>
</tr>
<tr>
<td>Jean</td>
<td>49</td>
<td>56</td>
<td>Married; status unchanged</td>
<td>Yes</td>
<td>Yes and has attended group</td>
</tr>
<tr>
<td>Katherine</td>
<td>28</td>
<td>33</td>
<td>Single; lived with parents at interview</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Krista</td>
<td>17</td>
<td>23</td>
<td>Single; later married</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Linda</td>
<td>36</td>
<td>42</td>
<td>Married; status unchanged</td>
<td>No</td>
<td>Not discussed</td>
</tr>
<tr>
<td>Liz</td>
<td>17</td>
<td>51</td>
<td>Single; later married and divorced</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Lorraine</td>
<td>38</td>
<td>55</td>
<td>Married; later divorced and remarried</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Maeve</td>
<td>31</td>
<td>37</td>
<td>Married; later divorced</td>
<td>Yes</td>
<td>Yes and has attended group</td>
</tr>
<tr>
<td>Maria</td>
<td>47</td>
<td>57</td>
<td>Married; status unchanged</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Ornella*</td>
<td>19</td>
<td>30</td>
<td>Lived with parents; later married</td>
<td>No</td>
<td>Not discussed</td>
</tr>
<tr>
<td>Peggy</td>
<td>37</td>
<td>48</td>
<td>Married; status unchanged</td>
<td>No</td>
<td>Not discussed</td>
</tr>
<tr>
<td>Sandy*</td>
<td>38</td>
<td>42</td>
<td>Divorced; status unchanged</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Shirley</td>
<td>48</td>
<td>57</td>
<td>Married; status unchanged</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sophia</td>
<td>44</td>
<td>52</td>
<td>Married; status unchanged</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Tanis</td>
<td>17</td>
<td>47</td>
<td>Lives with parents; later married</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Vicky</td>
<td>31</td>
<td>34</td>
<td>Partner; status unchanged</td>
<td>Yes</td>
<td>Not discussed</td>
</tr>
<tr>
<td>Violet</td>
<td>47</td>
<td>55</td>
<td>Married; status unchanged</td>
<td>No</td>
<td>Not discussed</td>
</tr>
</tbody>
</table>

*All names except those with a (asterisk) are pseudonyms. Starred participants asked to have their real names used, rather than a pseudonym. They have signed a statement to that effect.

Participants addressed these topics unevenly; there was no uniformity in terms of what was discussed in each interview.

Coding and analysis proceeded using grounded theory methods [21]. After the interviews were transcribed and verified for accuracy (transcripts were sent to participants for comment), the author and a research assistant read them several times for a general sense of what participants focused on and then independently developed coding schemes to represent understandings of participants’ various concerns (the research assistant worked on most of the transcripts...
but did not read or code all 28 transcripts). The process can be characterized as open coding [22] and every part of each interview was coded according to what the participant was talking about. For example, if a participant was talking about telling others about her stroke, the text was coded as “talking about stroke”. Other research assistants helped to focus initial coding (again, not all assistants worked with all transcripts). In reviewing the work completed by assistants, the author found that all understood and coded the interview transcripts similarly. The data were organized using the computerized indexing system QSR NUD•IST, a software package that allows for easy searching and retrieval of qualitative data. Analysis proceeded through constant comparison of interviews and coding [22] so that it became possible to discover common issues and themes. Previous articles have discussed two themes that clearly emerged from the data: the development of new priorities [23] and the problem of invisible disabilities [8]. As well, the author organized a selection of interviews into discrete narratives about the impact of the stroke and published these as a monograph [9]. The present paper focuses on another issue that clearly emerged from the interview data: the significance of age-similar peer support. The interpretation presented below has been shared with participants, and those who responded to a request for comments agreed that this is an important issue and approved of the author’s interpretation.

3. Results

In discussing the significance of age-similar peer support, this paper focuses on the recurring theme of feeling alone and misunderstood that was identified in all but six interviews and the desire for peer support that was discussed by all but seven participants. The benefits of reaching out to others are also briefly discussed.

3.1. Feeling Alone and Misunderstood. With few exceptions (see Table 1), participants talked about their interest in meeting and talking to another person who had had a stroke at a relatively young age. In general, reasons for wanting age-similar peer support revolved around feeling different from others on account of having had a stroke at a young age and consequently feeling isolated in the experience, alone, and/or misunderstood. Tanis, for example, was 17 when she had an aneurysm hemorrhage. She said,

_{I can only speak for myself, but I just felt so alone. And so isolated. Um, and that—maybe it was selfish, but—that nobody understood. This big TRAUMA that I'd gone through in me life, you know, and everybody else was out enjoying themselves and I was stuck at home, so I would have gone looking for support [had I known where to go]. Um, but I wouldn't have, I wouldn't have wanted um, any self-pity. I would have, I would have gone for the support. Yeah. (Interview 30 years after stroke)_

Similarly, Barbara who was 17 at the time, also, felt set apart from her peers because of what had happened to her. She talked of searching for literature that would explain her experiences to her, finally coming across the following:

_{… that magazine article called the “Charmed Circle of Survivors.” I had thought it was in Life magazine, although later I had tried to pursue it that way, and they’d said it wasn’t. But, and it was about um, young people who had survived cancer. And, that was the first time I’d ever read anything that really resonated with me. And it talked about them being a charmed circle survivors and how their experience was different from [pause] others. And that’s the—you know that, that was something that really made a difference to me. (Interview 30 years after stroke)_

Later in the interview, Barbara used the metaphor of going on a journey to elaborate on what it was like for her to know no one else who shared her experiences:

_{… in the beginning of [a Herman Hesse novel] he had a little, he had a little blurb about some, something about, the difficulty with making a long journey. It’s when you come back, and nobody else has had that experience. I’m paraphrasing. And so, it really changes your experience, or you do not have the opportunity to, discuss it or share it. And, and that was something that also meant a lot to me really, because that’s when I guess I felt, as if I’d been on a journey to a place where nobody else I knew had been. And, and that was very difficult to try to explain the, the event to—what I had seen, what I had experienced—to anybody because they had nothing to reference it to. So. So, I found that was [pause] it helped to explain to me what I was experiencing._

The youngest participant, Deirdre, was 8 when she had a stroke. She went from being academically advanced for her age to having significant cognitive difficulties. She talked poignantly about feeling isolated and misunderstood at school:

_{Um, I, sometimes, I mean, even when we got our last paper back and I got thirty-eight on it, you know, I EVEN got isolated then, or I felt isolated anyway, because I was talking to a second-year and she said, “oh, well, all the, you know, all the second-years have been through it too, you know … just take comfort in that.” And I was like [said with an angry tone]: “no, you haven’t, you haven’t been in my situation, you haven’t, you know, had a stroke, you haven’t, you know, gone from being quite intelligent to not intelligent at all and, you know, you haven’t been through everything that I’ve been through and so how can you say that?” You know, it was, it was almost, um—so it, it was quite nasty of her to say that … because I thought, well no you haven’t. Yeah, OK, you may have failed a paper or two, but you haven’t actually been through all the experiences that I’ve been through_
and you know, you haven't really been with me all my life, so how can you say that? Ummmm, and yeah, I'm—I mean, in school and in my, um, A levels and things, I DID feel isolated. I did feel isolated. (Interview II years after stroke)

Deirdre talked about how distressed she was when she was younger that she did not know anyone who had had a stroke, but then she became animated in talking about meeting someone else on the internet:

There's a girl on, on the net who's twenty. My age. I'm nineteen now, but, um, um, and she's had a stroke, she had a stroke about two years ago. So we, um—I have her MSN, um, email address—so, you know, we, we go on MSN chat. And we chat about our stroke and things like that and what, what difficulties we have and—so that's nice, I mean, previously I did not have any, anyone who'd had a stroke, or, you know, I did not know of anyone or anything like that. . . . I only found out about her about three months ago, four months ago. Um, we haven't really had a lot of chats and things but she's, she seems nice. I only know her, I only know her across the net but . . . her parents actually live in . . . the town where [I go to college now].

Author: So you might meet up?


Similarly, Liz, who was 17 when she had an aneurysm hemorrhage, was extremely angry about people who said to her that they understood what she had been through:

I do not know what your experience was but you, you have so many people saying to you, “I understand how you feel.” And so I cannot—there's nobody I can talk to, there's nobody that I can really sit and talk to about this. Because I cannot sit and listen, I just wanted to punch them in the face when they said that. You do NOT. (Interview 33 years after stroke)

As the preceding excerpts suggest, participants who were especially young at the time were quite clear about feeling different from others, and they continued to feel this even decades later. Yet, even those who were adults at the time of stroke talked of feeling different and searching for peer support. Brenda, for example, was 46 when she had an aneurysm hemorrhage. In preinterview email communications, Brenda said that she would like to meet others like herself, and the author recommended visiting a supportive internet site. She did so, and wrote,

Thank you Sharon for sharing this website with me, I wish I had this kind of information when I first took ill 7 years ago. I would not have felt so alone & misunderstood. I can relate to so many of the stories that were written.

When interviewed a year later, Brenda talked about searching for age-similar peer support where she lived but she was unable to find anything (interview 9 years after stroke). Her interview represented the first time she had ever met someone else who had had a stroke at a young age, and she was pleased to be able to talk about her struggles with someone who had similar experiences. For example, we had the following exchange:

Brenda: . . . the days [sigh] you struggle to even TALK so you have to, your brain is working all the time, so the more you work the brain, the tireder you GET [laughter]!

Author: Uh huh. Yeah, I, well, I know exactly what you mean, that everything—and trying to explain it to someone who does not know what—

Brenda: They do not understand. My husband tries, but he's still, not totally.

Jean, who at age 49 was the oldest at the time of stroke, started attending meetings for young stroke survivors when a local group formed. She said,

And they're brilliant because to get to a whole lot of people and compare notes and—I mean, the exercise is, obviously is very useful, but getting together with like people in the same boat and just finding you're not the only one. . . . I mean, whatever has happened to you, you discover when you say it to somebody, ”gosh, you wouldn't believe I thought or I did this,” and they say, “oh yes, so did I.” And you suddenly think you're not quite so crazy. (Interview 6 years after stroke)

Another who discussed the benefits of age-similar peer support was Grace, who was 35 when she had a stroke. Grace began attending meetings at her rehabilitation hospital while still an in-patient, and she continued attending until she moved away from the area four years later. When she first found out about the group, she said,

I was surprised. I really thought strokes happened to old people and that I was just an aberration and then I see all these young people. . . . [We] had a newsletter and uh, part of the, uh, part of the meeting, uh, we would discuss, uh, how we do things because uh, most of us are one-handed. . . . [We would] socialize too. I, I, uh, looked forward to seeing those people every one. (Interview 6 years after stroke)

3.2. Desiring Peer Support. The majority of participants did not have access to a group that met face-to-face (Table 1). Ida, for example, who had a stroke at age 38, had found a stroke survivors’ site on the internet and developed limited email correspondence with other survivors. Yet, Ida was left with cognitive challenges that made it difficult for her to take in a lot of written information at once, and she said that she
would rather be able to interact face-to-face with her peers (interview 7 years after stroke).

Sandy is another example of someone who would have loved to have had face-to-face peer support. She was 38 when she had an aneurysm hemorrhage, and she wanted to meet with age-similar peers:

*Um, but all the things that I was reading, were all saying the same thing: oh, normally when you have a stroke, you’re older. And I wanted someone who said, “yeah, but you can have one from the time that you’re born basically.” … I mean, I did join this stroke club in [a nearby town], a couple of years ago. Um, I used to go there and … at the end of it, I thought, I do not belong here, they’re all old people that have had it happen to them. And I do not belong here, and why am I coming here? (Interview 4 years after stroke)*

Helen, who had an aneurysm hemorrhage at age 32, was apparently left with no lasting impairment, although her sense of smell has suffered, and her stroke experience had a profound psychological impact. She said,

*I kind of felt like I wanted to talk to somebody. Um, somebody that had had it or somebody that knew about it. … Um, I remember trying to talk to someone at the, um, the Brain, I think it’s called the Brain Injury Support Group. And, you know, they did not think that I felt into their mandate. … But I do, I do sometimes, um, or I did sometimes, like when I said I wanted someone to talk to, and I went looking for someone to talk to, um, I, I kind of wondered why there was nobody to talk to. Like is it because there AREN’T people who, um, do as well as I do, or, or there must be SOMEbody and, and even if there is and it’s some- that person is worse off than me, am I going to be able to help that person, see, do you know what I’m saying? See, for them to see someone who’s sort of come, bounced right back. (Interview, 8 years after stroke)*

Lorraine, who had an aneurysm hemorrhage at age 38, was apparently left with no lasting impairment, although the subtle memory difficulties she developed afterwards may be a result of the stroke. Her lack of significant residual impairment, along with the fact that she had, and continues to have, an especially strong support network, means that she has never felt the need to seriously search for others who have survived an aneurysm hemorrhage. When she first learned of this research, she was not actively searching for peer support. Nevertheless, she said that when she came across the author's request for research participants,

*I thought, WOW! Cause I’ve not found anybody that’s survived one. … So, um, I, uh, I just wrote back, I wrote to you and said, “I had an aneurysm too.” And then I was just totally excited [laughter]! To hear, wow, there’s people out there! (Interview 17 years after stroke)*

Indeed, Lorraine repeatedly exclaimed that she was thrilled to be able to talk to somebody else who had survived an aneurysm hemorrhage, and several weeks after the interview, she wrote to the author to say that talking about her experiences had “actually put a lot of things to rest for me.”

Shirley, who had an aneurysm hemorrhage at age 48, devoted considerable energy to trying to find information and support but found little that was relevant to her situation:

*And I thought if you were writing something on it I was interested. Cause you cannot find anything. Or I haven’t found anything. Very little, as a matter of fact. Well, and I think it’s kind of needed. You know, because I really had no—I mean there is no such thing as preparing for this thing, but there would be such a thing as helping people, get, over it. … But, nobody, helped me. And I was seeing a shrink, before I had this, and I continued seeing one after I had this, and HE did not help. And I’m mad [laughter] I’m still mad about that [laughter]! I mean … I think he saw it as, over with. I mean, ok, you’ve had your appendectomy, now let us get on with it, you know. And that really is not kind of what happened. Or I did not think that was what happened. You know. (Interview 9 years after stroke)*

3.3. Reaching Out to Help Others. It was because of her experience of feeling she had no one to talk to that Shirley decided to start volunteering to help stroke survivors. She said,

*I volunteer at the nursing home now. And I’m actually one of them. … And, that has been helpful. To be ONE of them. To go in there and be one of them, and accept them like they are and, help them, and do my thing. That’s been a really, a positive thing. And I really like going there.*

In contrast to the majority of participants who did not have the support they wanted, Vicky had (and still has) a strong support system, including an especially supportive common-law partner. From the beginning of her stroke experience at age 31, she felt neither isolated nor misunderstood, but was able to talk about how she felt or what she thought about what had happened to her. Thus, when she contacted the Heart and Stroke Foundation, it was not in a search for peer support, but because she wanted to volunteer to help raise awareness about stroke in young people. With a background in communications, she became the media spokesperson

*And I, and I find that [pause] one of the best things I ever did after having the stroke was volunteer for the Heart & Stroke Foundation. [I do it] maybe as a warning to other people that, they should take their hypertension seriously. But also, it’s therapy for me. I get just as much if not more out of it, than other people get. You know, I’ve found talking about it very therapeutic. You know? (Interview, 3 years after stroke)*
4. Discussion

This research was intended to examine commonalities and differences across a number of variables. As discussed in this paper, one commonality found was that the women feel anomalous due to having had a stroke at a relatively young age. They typically feel alone and misunderstood. The theme of isolation is repeatedly expressed across the interview transcripts, and in many cases, there is an accompanying sense of despondency. Regardless of marital status (Table 1), their desire to talk to others who share the experience of surviving hemorrhagic stroke at a young age is palpable. This finding is congruent with findings about women with breast cancer [17], about women with MS [18], and about people with cancer [15]. As found in a study of spirituality for women with chronic illness, family and/or preillness friends lack the lived experience of illness; thus they are not able to offer the same quality of support as someone else who has "been there" [14]. At the same time, it is clear that survivors have their own ideas about who qualifies as a peer: Sandy, for example, did not see herself as having much in common with older stroke survivors.

Furthermore, a desire for peer support can exist for a long time after the actual stroke event. In this research, it was not related either to the age of the participant or to the length of time lived after stroke. Sandy, for example, was only four years after stroke when interviewed. Deirdre, who was the youngest participant and 11 years after stroke when interviewed, commented on wanting to meet others her own age, while Jean, the oldest participant at the time of stroke and six years after stroke, when interviewed, expressed a similar desire. Even Liz, at 33 years after stroke, felt a long-standing desire to talk to someone who shared similar experiences. Lorraine, meanwhile, at 17 years after stroke, found it helpful to finally be able to talk to a peer (i.e., the author). Even though not all participants were actively searching for peer support when contacted for this research (e.g., Lorraine), their comments suggest that peer support can be beneficial.

Even someone like Vicky who has a strong support network feels the need to reach out to others and talk about her experiences. She calls her media work therapeutic, which suggests that without this vehicle for self-expression, her sense of well-being would suffer. Vicky's experience can be compared to those of women with MS who benefited from offering telephone peer support [18].

Aside from talking to the author, some participants managed to find and maintain contact with others who share their experiences with stroke at a relatively young age. Without exception, connection with their peers helped them tremendously to feel better about themselves. As striking as it is to see women talking about feeling alone, it is equally striking to see the importance that those with real access to peer support attach to having the resource. Their comments in this regard echo other findings about the value of peer support for stroke survivors [16].

4.1. Limitations. Although participants in the present research were heterogeneous regarding age, geographical location, socioeconomic status, cohabitation status, length of time since stroke, residual impairments, and to a lesser extent with regard to race and ethnicity, they were in other respects homogenous. For example, countries of origin varied, yet all were living in industrialized, English-speaking countries. While there are subtle cultural differences between Canada, England, Scotland, and the United States (and there are striking differences between the countries in terms of the organization of health care), there are also broad similarities in terms of public discourse about social support, stroke, and perceptions about stroke. Thus, all participants shared similar ideas about the unusual nature of their experiences and with whom it is appropriate to talk about those experiences. Stroke survivors who do not subscribe to these broad cultural assumptions might feel very differently about the significance of their experiences. Certainly, it seems likely that stroke survivors who are elderly would not regard their stroke experience per se as unusual, and they might find that there are social resources available to support them in talking about their experiences.

As well, this research focuses exclusively on women's perspectives. Previous research on the issue of gender and hemorrhagic stroke has shown that men do not seem to be as likely as women to search for similarly situated peers with whom they can talk about experiences [19]. Yet, the fact that at least some men show such interest suggests that men, like women, may not be having their psychological needs adequately met. There is reason to suspect that the concerns reported in this paper may also be applicable to men. Further research on men's interest in peer support is warranted.

5. Conclusion and Implications

Recovery from stroke is a psychological as well as physical process. Psychologically, recovery from a trauma such as stroke can be a lifelong process. Lack of attention to the psychological consequences of stroke can lead to survivors having an impaired sense of well-being over the long term, and this needs to be taken into account in working with stroke survivors. The qualitative data presented in this paper, moreover, point to the potential usefulness of peer support for enhancing a sense of psychological well-being. Peer support is a unique form of social support and can be useful even when someone already has access to other sources of social support. At the same time, it is clear that survivors have their own understandings of who qualifies as a peer, and age is a central consideration. To be sure, there are internet sites offering peer support, but computer-mediated support, which may involve communication with others in very distant places, is quite different from having ongoing access to face-to-face support involving others in the same location. It is the latter type of support that research participants said they crave.

Equally clear, given the evidence that a desire for peer support can exist even for decades after a stroke, it should not be assumed that peer support is efficacious only during the immediate poststroke period. Any health professional working with a young stroke survivor needs to keep in mind the possibility that survivors, even though they may have returned to the community decades ago, may feel alone and
misunderstood. Access to peer support might help to alleviate such feelings.

Conflict of Interests
The authors declare that they have no conflict of interests.

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