

Growing older with post-polio syndrome: Social and quality-of-life implications

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Abstract

Objectives: To understand the quality-of-life implications for post-polio syndrome survivors.

Methods: For this qualitative study, a focus group methodology, with a case study design, was used. The data were analyzed for themes using a social ecological conceptual framework.

Results: Three focus groups were conducted with a total of 24 participants (N=24). Participants defined quality of life as being able to engage in meaningful activities of daily living. Participants shared experiences of adapting to declining physical health and embracing new activities of daily living. They expressed hope and shared stories that demonstrated resiliency.

Conclusion: The literature states that individuals aging with post-polio syndrome express concern that health providers often know little about their disability condition. The participants in this study reflected this experience by sharing feelings of misunderstanding from the medical community and expressing a desire to have more dynamic education for health providers.

Keywords

Post-polio syndrome, aging, quality of life

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Poliomyelitis (polio) was one of the most notorious diseases of the 20th century, yet its impact and devastating consequences are a distant memory for many Canadians. Between 1927 and 1962, almost 50,000 Canadians were infected with the poliovirus, but that number declined drastically with the development of the polio vaccine in the mid-1950s.¹ Canada was declared polio free in 1994, and since then, Canadian efforts have shifted to focus on polio prevention. With polio on the brink of global eradication, often forgotten is the vast number of people who have lived with polio sequelae since the initial infection and those who are affected by post-polio syndrome (PPS).²

PPS typically occurs in polio survivors after at least 15 years of stability and manifests as new weaknesses, central and peripheral fatigue, musculoskeletal pain and atrophy of previously unaffected muscles.³ The reported rate of PPS among polio survivors varies greatly, with the prevalence rate varying between 20% and 75%.³ PPS can affect bodily functions, mobility, and physical strength, impacting an individual's ability to maintain an independent life.

There is a moral obligation to continue to engage in polio survivor service provision and research, even after the elimination of new polio cases, by providing support and services to polio survivors who face health consequences and social exclusion.⁴ Today, the number of Canadians living with PPS

is unknown, but the prevalence of PPS among polio survivors has been reported to be between 25% and 40% according to the Centers for Disease Control and Prevention (CDC)⁵ in the United States of America. Similar to other developed countries, it is expected that the majority of Canadian residents living with PPS have reached retirement age and may experience disability due to the combined effects of PPS and older age.⁶

Due to the lower number of individuals living with PPS, it is unsurprising that there is a dearth of new research identifying effective clinical interventions for PPS.⁶ In the absence of effective clinical interventions, Lam and McNalley⁶ emphasize that education is among the most valuable of services a physician can provide to a patient with PPS, particularly regarding the normalization of typical symptoms such as fatigue. Energy conservation measures

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Table 1. Age and age of diagnosis of study participants.

	Mean	Standard deviation	Range
Age (years)	72.46	8.82	55–97
Age of polio diagnosis	4.15	43.15	6 months to 11 years

are commonly recommended for people with PPS and are increasingly important as one experiences the combined effects of aging and PPS. This includes pacing of physical activities to avoid overuse, combined with frequent rest periods, weight loss programs, and use of assistive devices.⁷

Beyond the clinical perspective, it is also important to consider community-based supports and services that may ameliorate the symptoms of PPS and prevent or mitigate the onset of secondary health conditions. The objective of this study was to understand the quality-of-life implications for PPS survivors. Specifically, the researchers hoped to build an understanding of the following questions: (1) what constitutes “quality of life” for individuals aging with PPS, (2) what are individual and environmental factors promoting a high quality of life, and (3) what could augment existing social programs and services to improve the quality of life for this population.

Methods

For this qualitative study, a focus group methodology, with a case study design, was used. Participants were recruited through *Post-Polio Canada*, which is a program of March of Dimes Canada dedicated to the creation of peer support groups and networks of polio survivors.⁸

During the conference, *Post-Polio: Aging with Dignity and Strength* on 26 and 27 May 2017 at YMCA Geneva Park, in Orillia, Ontario, participants were invited to participate in semi-structured focus groups, where they were encouraged to share their perspectives on quality of life while aging with PPS. Two time slots were available for eligible participants with the goal of including as many participants as possible. Participation in a focus group was not a mandatory activity for individuals attending the conference. Due to increased interest, a third additional focus group occurred on 19 July 2017 at March of Dimes Canada’s head office, in advance of a post-polio peer support meeting. Again, participation was voluntary. It was noted by the third focus group that saturation was reached and therefore the researchers felt a sufficient sample size was achieved.

All three focus groups were facilitated by one of the principal investigators (A.D.). The focus groups were audio recorded. A second principal investigator created a speaking transcription template that identified the participant number and the first few words of their contribution. The entire recorded audio was transcribed verbatim. The transcription

template was used to ensure that participant number could be identified during data analysis.

Each focus group was facilitated in an effort to answer six open-ended questions. These can be found in Online Appendix 1. Each focus group was 60–90 min in length.

The transcripts were entered into NVivo11 and then coded for themes. The two PIs collectively developed the codes and nodes for the data analysis, using the Social Ecological Framework, and then jointly coded the transcriptions from one focus group. Then each PI individual coded one of the focus groups independently. This coding was then reviewed by the other PI. Any alternate conclusions were discussed until consensus was derived.

This study received ethical approval from the University of Toronto’s Ethics Review Board on 28 April 2017.

Social ecological framework

The data were analyzed for themes using a social ecological conceptual framework. Social ecological frameworks are ubiquitous in the fields of public health, sociology, biology, education, and psychology^{9,10} and account for the impact of an individual’s social and environmental context on their health outcomes.^{11,12} An ecological perspective has been embraced in community health promotion as it emphasizes the dynamic interaction of intrapersonal and environmental factors equally, rather than targeting lifestyle interventions that place the onus solely on an individual.¹² For this study, the main constructs of this framework were used as themes for the data coding. Analysis of the themes occurred within the constructs.

Results

Three focus groups were conducted with a total of 24 participants (N = 24). The age of the focus group participants ranged from 55 to 97 years of age, with the majority of participants born in Canada and female. Please see Tables 1 and 2 for demographics of study participants.

Individual

Individual factors relate to a person’s level of knowledge, skills, and attitudes toward their unique life experience, including how an individual defines quality of life.

Beliefs (quality of life). Quite universally, participants defined quality of life as being able to engage in the activities of daily living. This was consistent among all participants and across the three focus groups. As the participants engaged in this aspect of the discussion, they often went on to provide examples of how they are continuing to engage in meaningful activities. Volunteering, travel, and meal preparation were the most commonly cited activities that participants reported they continue to enjoy and which they feel contribute positively to their quality of life.

Table 2. Age of PPS onset, sex, and country.

	N	Percent	Mean	Standard deviation	Range
Age of PPS onset					
Known	11	46	47.18	7.39	36–60
Unknown	13	54	N/A	N/A	N/A
Sex					
Male	5	21			
Female	19	79			
Country of birth					
Canada	15	63			
England	4	17			
Hungary	1	4			
Pakistan	1	4			
Philippines	1	4			
Taiwan	1	4			
Yugoslavia	1	4			

PPS: post-polio syndrome.

However, the discussion on quality of life also led some participants to share examples of activities they feel they can no longer participate in. Housework and cleaning were the most commonly cited examples of activities that participants report they can no longer complete. A few participants reported that they have made efforts to complete housework recently, and it caused a significant increase in pain and weakness:

I do have a cleaning lady. I had to give up cleaning. I tried to clean and it made me so much worse when I was cleaning. After cleaning, I'd be in bed. So I've had to give up a lot. (Female, Age 74)

Changing functional needs. Further to the concept of quality of life, this increasingly led participants to discuss the change in their physical selves and how this has impacted their lives. Most specifically, many shared that their physical bodies have become weaker and they have decreased activity tolerance. They feel that their physical health is declining, but also expressed a willingness to adapt to these changes.

In addition, the participants shared that their experiences with declining physical strength and mobility is more marked by PPS and the aging process. It was noted that while they had experienced weakness at a younger age, many went on to live active lives, and now the symptoms are returning. There was a sense that they had thought they had “survived” or “beat” polio:

And things are getting difficult in a lot of ways. And we need to find a way to stop that. Because we had a disease, we got over the disease, we got on with our lives for 20, 30 years, and suddenly something else happened to us. And now we've got to cope with that in a world that's not prepared for us. (Female, 72 years old).

During this portion of the focus group, in all three focus groups, the participants shared more emotional feelings about the changes that they are experiencing:

I started talking about my experience as a child having had polio. And I had suppressed everything. I'd pushed all my feelings down. I didn't deal with them. And then all of a sudden, the flood gate opened up and it was like I just ... I cried. It was embarrassing. (Female, 70 years old)

Many participants felt that the change in their physical selves was impacting quality of life. In addition, a few participants shared a fear of how their physical status will change in the future:

I'm still in pretty good shape but I'm scared about the future. (Female, 72 years old)

Knowledge and understanding. In general, the participants appeared to have a strong understanding of polio and PPS. Specifically, they were well educated on symptom management and energy conservation. Many demonstrated an understanding that it is important to conserve energy and shared tips and strategies within the groups about how to maintain physical activity without causing excessive pain. Further to this, a few members shared that they have done their own research and self-diagnosed themselves with PPS. Despite presenting as a well-informed group, most participants also expressed a desire for more education. One participant stated:

... research and knowing about exercises. I know we have to be careful not to overdo it. But being aware, being informed about new developments, about new research that will help us maintain our physical abilities as much as possible. (Female, 66 years old)

Many other participants expressed a similar desire for more education and understanding. Specifically, participants expressed that they have outstanding questions about new medical information, emerging technologies, available services, funding, home modification options, and pain management strategies. A few participants expressed that as polio has left the social stage less information and public education has been available.

Attitude. Although the participants in the focus groups shared frustrations, emotions, and desire for a different health state, by no means was this the majority of the subtext of the conversations. The majority of group participants shared stories and examples of their commitment to continuing to build a life full of meaning. They expressed hope and shared stories that demonstrated significant resiliency. The participants shared that having a good quality of life is sometimes about having the right attitude:

I'd rather be happy and cheerful and appreciate what I have. In fact, when I went on that cruise, the post-polio cruise, there were post-polios [...] from all over the States, and some of them are much worse off than me. And they were praising and thanking God for what they had. You know, that's the right attitude. (Female, 70 years old)

Other participants shared that part of having hope and resiliency is about changing the expectations you have for yourself and your abilities:

Well, of course you have to change your way of thinking when it comes to quality of life. If you can't do what you used to be able to do then you have to be I guess happy to do what you can do. And I've had to give up that feeling that if I couldn't do it then I wasn't good enough. (Female, 70 years)

Interpersonal relationships

The Social Ecological Model of Health considers *Relationships*, also termed Interpersonal, as factors connected to an individual social network, including family and friends.

The participants uniformly expressed the importance of relationships on quality of life. While the research questions were not specific to relationships, the importance of relationships arose frequently when the participants were asked to share factors that enhance their quality of life. Relationships were often cited as factors that positively impact their quality of life.

More specifically, spouses, siblings, adult children, and grandchildren were most frequently referenced as positive relationships in the participants' lives. Most specifically, the family members were referenced as providing help with personal care, transportation, and emotional support. Many people reported that their family members provide understanding and validation.

Quite a few participants also spoke about the loss of a spouse. Stories were shared about how their lives have changed since the death of a spouse. Participants cited needing more external support and needing to be creative to maximize independence after this change in family.

While the majority of participants shared stories of positive relationships and their beneficial impact on their quality of life, not all participants stated that their personal relationships were a source of positive influence on their quality of life. Specifically, a few participants shared frustrations when their friends didn't understand their physical limitations and no longer included them in social activities. In addition, a few participants shared that they did not have positive relationships with their adult children and do not feel supported.

In general, all participants shared that social relationships were important and, whether family or friends, social relationships have an impact on quality of life. A few participants reference the Post-Polio Canada conference and other peer support groups as an important source of relationships and support:

I do really appreciate that we have support groups, and I get to meet other people that are in similar situations and listen to their stories and how they're coping with what they're going through. (Male, 74 years old)

Community

The Social Ecological Model of Health typically has a level for *Organizational*, addressing organizations, schools and workplaces, and a level of *Community*, addressing design, access and connectedness. Based on the findings in the focus groups, it was relevant to merge these two categories and consider themes for *Community* considering all of these factors.

Medical community. When the focus group facilitators asked questions about how the participants' quality of life could be improved, some participants discussed factors and issues related to the medical community. More specifically, participants talked about a general misunderstanding of PPS among the medical community:

And then I found that doctors, even doctors, they looked at me with horror or surprise—"Polio? Well, we don't learn about polio. It's gone. We don't learn anything about polio. So I don't know how to treat it. That's over." (Female, 74 years old)

The participants shared that there is a general lack of understanding and education in the medical community about PPS and how it should be treated. Many participants reported they feel dismissed by their health professional, or that there was a sense that there was nothing available to address physical symptoms and limitations:

We need more doctors taking an interest. Because we're aging, we had a first disability, but because we're having problems now with other things, they sort of look at us and say, "Oh, it's all just your polio." They don't think, "Well, okay, they have polio but now we've got this other problem that's occurring." (Female, 72 years old)

However, not all participants shared negative experiences with the medical community. Several participants shared the names of health professionals who both understood PPS and also offered symptom management, and other participants were eager to obtain their contact information:

Years ago when I went to physiotherapy ... it happened that the physiotherapist was back from a tour in Vietnam. She knew about polio. She was training a young guy who had never heard of polio, showing him ... So that was positive to me. (Female, 76 years old)

In general, when asked about how quality of life could be positively impacted, there were many participants who requested that there is increased education for health professionals about PPS. As all three focus groups were

conducted in collaboration with March of Dimes Canada, there was discussion about any activities that MODC could do to support the participants' needs. A few responses were connected to the need to develop initiatives and programs to increase education among all health professionals:

The only thing that comes to my mind is educating the medical people. And that includes the nurses and anybody who is taking care of us. And it doesn't have to be like a big thing. (Female, 72 years old)

Service. Participants also shared aspects of community services that are both helpful to building their quality of life, or deemed absent, and thus negatively impacting their quality of life. A common theme was transportation. Participants who lived in urban geographies discussed the benefits of accessible transportation, while those in rural areas shared frustration that transportation was not available which negatively impacts their quality of life:

Our local bus service ... if you're in a wheelchair ... you don't receive door-to-door service. They can pick you up and drop you at a bus stop. In the middle of January in a snowstorm, you're supposed to sit at a bus stop and wait for a bus to take you somewhere else, and then transfer over all the snow onto another bus because they're not having door-to-door service. (Female, 72 years old)

Participants also shared that they use personal support services to assist with personal care, housekeeping, and outdoor maintenance. Many shared that allowing others to perform housekeeping activities provided freedom to engage in other activities that lead to an increased quality of life. This topic often lead to funding discussions. Some participants shared that they pay out of pocket for these types and services, while others shared that they would like to advocate for more funding in the future:

But I also would like things to be covered by OHIP ... I mean all that comes out of my pocket. It's not covered. (Female, 72 years old)

A few of the participants also expressed a desire for more services targeted at social programming. Specifically cited were an interest in organizations that host social outings, such as to a sporting event, or events, such as picnics or barbecues.

Public policy

The last level of the Social Ecological Health Model is public policy. This section has to do with national, provincial, and territorial laws and policies. Issues and themes that arose in the focus groups were related to "assistive technology" and "advocacy and funding." Both of these factors were cited by participants as having an impact on their quality of life.

Assistive technology. The vast majority of participants appeared to use some form of mobility device to transport themselves. Canes and crutches, walkers, power wheelchairs, and scooters were all devices that were used by the participants. When asked about things that support their quality of life, many participants referenced their mobility devices as a factor that enhances their lives:

But I have to tell you, I love the chair. This may be weird. Like it's my mobility. And actually once I went into the chair, I found I could do a lot more than what I could on crutches and braces because I could carry things, I could get things, bring them where I wanted to, and I didn't have to wait for someone else to do it. And I think actually what going into a chair teaches you is ... Like not so much a power chair but any kind of a wheelchair, is that it teaches you patience. (Female, 70 years old)

While this quote is reflective of many of the comments made by participants, a few participants also reflected that they were initially resistant to using mobility equipment. Stigma and fear of accepting the physical decline were reasons stated; however, all participants who shared this sentiment also shared that they no longer feel this way about their mobility device.

Many participants also shared that there are other assistive technologies that are having a positive impact on their lives. Car hand controls, bathroom and kitchen modifications, stair glides, and wheel-in showers were all cited as beneficial technologies to allowing the participants to engage in their activities of daily living with less difficulty and more independence.

In terms of accessibility in the community, a few participants shared that they "think the government has done really well in providing things like ramps and elevators and places to sit." However, others shared frustrations with facilities and public spaces that are still not yet accessible. This barrier was reported as negatively impacting participation in social activities, thus negatively impacting quality of life.

Funding. Further to the notion of accessible community, many participants expressed views on the theme of advocacy. While some participants have experienced positive changes in their community to make the environment accessible, others have felt that they have had to advocate for accessibility to be addressed in their community:

And I also have gotten involved in the accessibility issues in Ontario and municipalities and all that kind of stuff ... But it's also very disturbing when you know that there's a problem, and you say something, and they go, "Yeah, but you're the only one. We don't have to fix it. No one else needs it." And you know the people are having problems, you know that your municipality is not following the statutes ... This is 2017, and the Act started in 2001. (Female, 72 years old)

Participants expressed a desire for more funding and called upon agencies such as March of Dimes Canada to provide

more funding and to advocate for more funding. Specifically, funding for home modifications and mobility equipment were referenced during the discussion.

Discussion

PPS can occur after 40 years of stable health in post-polio survivors. There is no cure for polio or PPS, a condition affecting polio survivors years after partial or complete functional recovery from the initial acute attack of the polio virus.³ PPS is estimated to affect 15–20 million people globally and is prevalent among 20%–75% of polio survivors.³ It manifests as new weaknesses, central and peripheral fatigue, musculoskeletal pain, and atrophy of previously unaffected muscles.³

Although there is information on diagnostic and treatment options for individuals aging with PPS, a chief concern among individuals aging with PPS is that community providers and family physicians often know little about their disabling condition.^{13–15} The participants in this study reflected this experience by sharing feelings of misunderstanding from the medical community and expressing a desire to have more dynamic education for health providers. Advances in the provision of care, such as improved communication skills of health providers and instantaneous access to information, has the potential to be of great benefit to people aging with PPS, and their unique perspectives must be included in policies and programs that compose the wider health and social care systems.

Although focus group participants lamented the lack of knowledge regarding PPS among healthcare professionals, there was also a willingness to adapt to changes in function. Focus group participants were eager to share recommendations and suggestions with one another and to advocate for increased supports and services promoting increased accessibility in public spaces and funding for assistive technology and home modifications. Individuals growing older with a disability are often supported by both the aging and disability sector. The aging field is often seen through the lens of the biomedical model of health which focuses on preventing and curing medical problems causing disability. Whereas, the disability field has developed through a social model of health, which focuses on building inclusive environments and eliminating systemic barriers. By understanding the perspective of individuals aging with PPS using a social–ecological framework, it allows for a deeper understanding of this human experience as individuals are aging and their disability is changing. Use of this lens enables educators, health professionals, and researchers to understand that coping strategies are very important to allowing individuals to adapt to changes in function as they age with PPS.

PPS and quality of life

Understanding quality of life rated by individuals with PPS is of interest due to the notion that many individuals who

experienced polio as a child became overachievers in comparison to individuals with a disability and the general nondisabled population.¹⁶ In addition, they are employed at a rate of four times that of the general population of individuals with disabilities and an equal percentage are married and have family responsibilities as the able-bodied population.^{17,18} The study participants reflected this concept and dynamic expression. Despite having daily challenges in their physical and social environments, the study participants presented themselves with strength and tenacity, and expressed a willingness to adapt to the changes in their function as they age.

In 2013, a qualitative study on the perception of the meaning of quality life and strategies to foster participation among polio survivors was conducted by Atwal et al.¹⁹ The authors recognized that the majority of research on PPS has focused on health status rather than its effects on quality of life. This study used data from an existing survey conducted by the British Polio Fellowship, and 366 people completed the questionnaire of which 61% were women and the average age was 54 years. The first question analyzed by the researchers asked how health affected the individuals' quality of life, and responses were categorized in two broad themes by the authors, "life-limiting" and "avoidable limitations." Life-limiting activities included how the symptoms of PPS affected individuals' engagement in activities they enjoy, their decisions to retire early and the impact upon their relationship with family members due to pain, lack of strength and stamina among other symptoms of PPS. Environmental limitations address situations where the environment prevents participation in certain activities. The primary issues included lack of accessible public spaces and friends' homes, as well as the knowledge and attitude of health professionals. Similar to Yorkston et al.,¹⁵ participants lamented that doctors or the healthcare professionals do not recognize PPS.

The second question in this study asked participants to describe one thing they would like to change to improve their quality of life. Responses related to individuals' impairments or health conditions often addressed fatigue, as well as the desire to retain their level of functioning. In addition, participants stated that a better understanding of PPS from family members and able-bodied individuals would increase tolerance and noted that social isolation, accessible environments, lack of additional income to enable them to purchase assistive technology or services to maintain independence, and lack of access to healthcare services and professionals who were knowledgeable about PPS and/or were more interested were issues that impacted their quality of life.

Limitations

This study presents a few limitations. The most significant is the homogeneous nature of the research participants. All participants were recruited through Post-Polio Canada, and therefore, one may assume that this is a motivated and well-informed group. They may not be representative of the larger

PPS survivorship. In addition, the focus group design may have influenced the opinions and statements of participants, and the two principal investigators coded the interviews (rather than an independent study team trained in coding), which may reflect personal biases given their interest in the subject matter.

Conclusion

There is limited evidence on the experience of aging with PPS. Health conditions often affecting older adults with PPS include, fatigue, pain, and muscular atrophy. In addition, individuals aging with PPS may be more likely to experience secondary health conditions due to their impairments. Society will continue to grapple with the effects of polio and PPS for decades to come, but because efforts have shifted to prevention and eradication, it is possible that polio survivors will not receive the attention from policy and program planners that they deserve. By reviewing the needs and issues addressed by older adults with PPS, it is clear that some of the issues are similar to that of the aging population, and significant resources are being acquired to address these issues. Thus, now is an opportune time for older adults with PPS to ensure that policies and programs for the general aging population are inclusive to those with PPS. In addition, understanding the process and needs of older adults with PPS may offer insights to improve quality of life for older adults who are aging into disability, as well as individuals who are aging with other long-term disability. It is important that all stakeholders are aware of these issues and work collaboratively to find solutions. Researchers should focus on continuing to understand the emerging and changing needs of this unique population. The healthcare community needs to ensure that they maintain educational programming so that tomorrow's healthcare providers know how to assess and treat this condition. Finally, policy makers, funders, and community program providers need to continue their efforts to ensure that fair and equitable programs, funding, and support are available to PPS survivors. By working collaboratively, we can ensure that this marginalized population is included and provided with the care they deserve.

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