



Growing up with a disability following paralytic poliomyelitis: experiences from persons with late effects of polio

Catharina Sjö Dahl Hammarlund, Jan Lexell & Christina Brogårdh

To cite this article: Catharina Sjö Dahl Hammarlund, Jan Lexell & Christina Brogårdh (2019): Growing up with a disability following paralytic poliomyelitis: experiences from persons with late effects of polio, *Disability and Rehabilitation*, DOI: [10.1080/09638288.2019.1647296](https://doi.org/10.1080/09638288.2019.1647296)

To link to this article: <https://doi.org/10.1080/09638288.2019.1647296>



© 2019 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



Published online: 06 Aug 2019.



Submit your article to this journal [↗](#)



Article views: 983



View related articles [↗](#)



View Crossmark data [↗](#)

Growing up with a disability following paralytic poliomyelitis: experiences from persons with late effects of polio

Catharina Sjö Dahl Hammarlund^{a,b} , Jan Lexell^{a,d}  and Christina Brogårdh^{a,c} 

^aDepartment of Health Sciences, Lund University, Lund, Sweden; ^bThe PRO-CARE Group, School of Health and Society, Kristianstad University, Kristianstad, Sweden; ^cDepartment of Neurology, Rehabilitation Medicine, Memory Disorders and Geriatrics, Skåne University Hospital, Lund, Sweden; ^dDepartment of Neuroscience, Rehabilitation Medicine, Uppsala University, Uppsala, Sweden

ABSTRACT

Purpose: To describe the experiences of growing up after acute paralytic poliomyelitis and strategies used to adapt to the new situation.

Methods: Seven women and seven men (mean age 70 years, min–max 61–78 years) with late effects of polio, who had contracted paralytic polio in their childhood. Data were collected using semi-structured interviews, transcribed verbatim, and analyzed by systematic text condensation.

Results: Memories of contracting acute paralytic poliomyelitis involved being immobilized and sent away from home for surgical and physiotherapeutic treatment. Growing up in a social context that was often tough and unfriendly resulted in the development of strategies, such as optimistic thinking, trying to blend in, trusting one's ability to manage, and to handle the preconceptions and expectations of others. At the onset of late effects of polio, some of these strategies were still functioning, whereas overachieving, disregarding pain, and weariness were not.

Conclusion: The challenges of growing up with a disability following paralytic polio led to the development of various psychological strategies for managing daily life. By understanding these experiences and strategies, knowledge may be gained in assisting rehabilitation professionals to better support persons with late effects of polio in adapting to the new situation.

ARTICLE HISTORY

Received 9 December 2018

Revised 13 June 2019

Accepted 19 July 2019

KEYWORDS

Coping skills; psychological adaptation; physical activity; paralytic polio myelitis; qualitative methods

► IMPLICATIONS FOR REHABILITATION

- At the onset of late effects of polio, strategies developed earlier in life, such as overachieving, disregarding pain, and weariness, may not function anymore.
- Understanding the experiences of growing up with poliomyelitis can support rehabilitation professionals to provide targeted interventions for people with late effects of polio and enable them to develop new adaptive strategies.
- Developing new strategies, such as accepting increased symptoms, and augmenting self-esteem and self-efficacy, may improve daily functioning among people with late effects of polio.

Introduction

Numerous people who have suffered from acute paralytic poliomyelitis in their childhood become aware of new or increased impairments several decades later, referred to as late effects of polio [1]. Common impairments following late effects of polio include muscle weakness, muscle fatigue, general fatigue, and musculoskeletal pain [2–7]. The new or increased impairments often lead to various activity limitations [8–13], restriction in social participation, and reduced life satisfaction [14,15].

Even though this condition cannot be cured, people with late effects of polio can benefit from an individualized goal-oriented, interdisciplinary rehabilitation program [16]. In order to maximize each individual's physical, mental, and social capacity, they were taught the implications of late effects of polio together with self-management strategies, thereby experiencing a turning point in life. Before taking part in this program, they felt that they were on a downward slope without control. At the onset of late effects of

polio, they felt as if they had caught polio a second time, as they reexperienced symptoms that brought back memories of struggles from their past (i.e., the acute polio infection during childhood) [9,10,16]. They also felt alienated from their previous self and were unsure what their future would bring. The interdisciplinary rehabilitation program helped them to reflect on their self and go through a process of change in order to adapt to a different but good life [16].

Acute paralytic poliomyelitis of one or several limbs, or sometimes the whole body, restricted mobility and affected their entire life situation when growing up. Some were sent away from home for weeks or months to be treated in specialized hospitals [17–19]. They became dependent on other people, which seemed frightening at the time [18–20]. Visits by parents or relatives were not allowed because of the risk of catching concurrent infections [17]. Children who showed signs of emotional instability and behavioral problems after being hospitalized had sometimes been separated

CONTACT Catharina Sjö Dahl Hammarlund  catharina.sjodahl_hammarlund@med.lu.se  Box 157; SE-221 00 Lund, Sweden

© 2019 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

from their parents for a long time, not knowing what was happening to them [21]. These childhood experiences shaped them for the rest of their life, which may have resulted in self-alienation, overachieving at work, and striving to fit in [9,18,19,22,23].

Experiences whilst growing up may influence a person's ability to handle late effects of polio. It is therefore important to better understand reactions and strategies related to the circumstances and challenges of growing up and strategies for overcoming these difficulties. Increased understanding of these experiences may support clinicians to better individualize the rehabilitation interventions and thereby facilitate a positive process of change in persons with late effects of polio.

The aim of the present study was therefore to describe the experiences of growing up after paralytic poliomyelitis and strategies used to adapt to a new situation.

Method

Research design

This study was part of a larger project aimed at understanding experiences of living with late effects of polio with regard to falls [8], ageing [9], and growing up with the consequences of polio. A qualitative research design with individual interviews was used, as such a design allows us to explore an insider's perspective of the phenomenon [24]. In this study, only data from interviews related to the participants' experiences of growing up are presented.

Participants

Fourteen participants, seven women and seven men, mean age 70 years (min–max, 61–78), were strategically selected [25] from a rehabilitation clinic in southern Sweden with regard to gender, age, and time since the onset of late effects of polio [12]. The mean age for contracting the acute paralytic poliomyelitis was 4 years (min–max 1–12), and the mean duration of late effects of polio was 26 years (min–max 9–43). All had an established history of acute paralytic poliomyelitis with new symptoms following a stable period of at least 15 years and clinically verified late effects of polio. Four participants had part-time disability pensions, 10 had old age pensions, and 11 were cohabiting.

Ethics

The Regional Ethical Review Board in Lund, Sweden, approved the study (Dnr: 2014/186). The principles of the Declaration of Helsinki were applied, and all participants gave their written informed consent after receiving written and oral information about the study.

Procedure

Data were collected by two of the authors, (CB and CSH), using semi-structured interviews (lasting on average 70 min, ranging from 60 to 90 min), that were recorded and transcribed verbatim. Each interview started with an introductory sentence: "The aim of this interview is to better understand your experiences of how paralytic polio has influenced your life situation both in the past and now that you are ageing with late effects of polio." The interview guide included areas of interest such as the following: (a) experiences of growing up with the consequences of paralytic poliomyelitis, (b) managing everyday life situations, and (c) strategies in managing perceived difficulties. Open questions were used to encourage the participants to elaborate on the narrative, for example "Can you

give an example?," "Can you clarify what you mean?," or "Could you elaborate on this subject?"

Data analysis

Data were analyzed by systematic text condensation as described by Malterud [24]. The first step was to read each transcript in order to get a general sense of the data and to identify primary themes. Next, meaning units, i.e., parts of the text that contained information that was relevant to the research questions, were uncovered and formulated into codes. During this phase, two of the authors (CB and CSH) worked independently to find various perspectives and nuances of the material. Thereafter, the coded data from both authors were integrated into one set of data and duplicates were removed. The coded data were structured into subcategories by their conceptual representation, and the contents of the meaning units of each category were reviewed. From this analysis, the abstracted meaning was formulated to represent the content of the subcategories, which were then organized into categories. To make sure that no important aspects had gone unnoticed, the clusters were referred back to the raw data, which were read through by all three authors. Finally, conceptual descriptions reflecting the meaning of each category were expressed and representative quotes were selected for each category/subcategory.

Results

The analysis uncovered a number of subcategories, which were then put into three categories. (1) "Memories of falling ill, being immobilized and needing physical treatment" consisting of four subcategories: (a) *Disabilities following acute paralytic poliomyelitis*, (b) *Being sent away for treatment*, (c) *Surgical treatment and physiotherapy*, and (d) *Orthoses to facilitate mobility*. (2) "Managing social encounters and living up to the expectations of others" comprised four subcategories: (a) *Alienation due to activity limitations*, (b) *Feeling looked upon as different*, (c) *Meeting peers and making friends*, and (d) *Managing a situation without complaining*. (3) "Various psychological strategies for adapting" contained three subcategories: (a) *Trying to blend in*, (b) *Choosing to focus on positive aspects of life*, and (c) *Building a self-image and trust in the ability to manage* (Figure 1).

Each quotation has been assigned a code with gender, a capital letter representing a fictitious name and age when contracting polio (i.e., above or below the mean of 4 years) and the duration of late effect of polio (i.e., above or below the mean of 26 years).

Memories of falling ill, being immobilized, and needing physical treatment

Most of the participants had very clear memories of how they felt when they contracted polio. The memories of those who were very young at that time were more fragmented. All, however, remembered that their body had changed and was not functioning as it did before they fell ill. They were subjected to various treatments that were painful and meant using clumsy orthoses.

Disabilities following acute paralytic poliomyelitis

In the acute phase, the participants remembered that they felt as if they had a fever or maybe a cold. Most of their memories were hazy and blurred. However, they remembered that they could not walk, and that one leg or foot had stopped growing and was thinner and smaller than the other one. Other symptoms were pain and cramp in the affected limb.

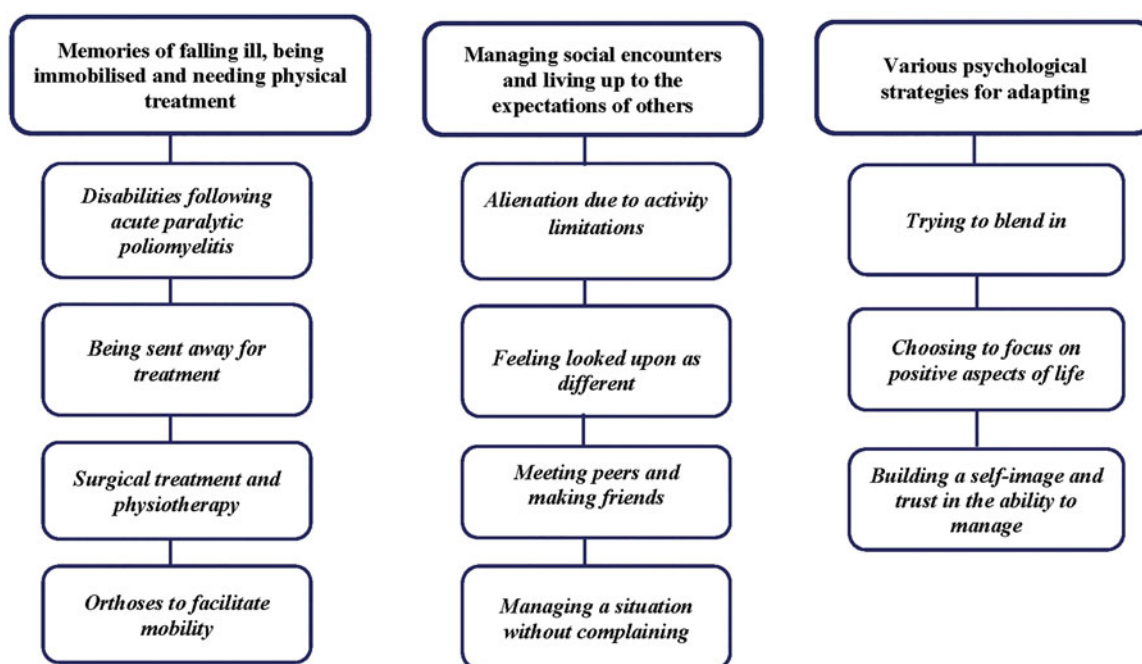


Figure 1. Overview of the results describing the experiences of growing up and strategies for adapting to disabilities following paralytic poliomyelitis.

Because as you see now, I easily get cramp ... which I've had since I caught polio. I can remember that ... lots and lots of leg cramp at night and at that time, when I was seven, I was told that I mustn't have anything heavy on my feet. So that blankets and stuff like that had to hang over the footboard ... I wasn't allowed to put any weight on my feet. [Woman E: >4 years at onset of polio; <26 years of late effects of polio]

Being sent away for treatment

All participants had been sent away for specialized treatment. For some, it meant that they were only allowed to come home during school holidays as the distance between their homes and the clinic made commuting out of the question. They described the sorrow that parents and relatives had shown when they were separated from their child.

In those days... it left my mother with a profound sense of loss and sadness until the day she died. She was always very sad that they had handed me over and sent me away, as she used to say.... I mean, we were living in the countryside... and I was sent to a far off hospital ... [a specialised clinic far from home] ... and there I stayed... [Woman A: <4 years at onset of polio; >26 years of late effects of polio]

Surgical treatment and physiotherapy

Some participants had undergone several operations seeking surgical solutions to compensate weak muscles and asymmetric leg lengths. Sometimes, these operations were unsuccessful and only caused more problems and pain. Physiotherapy was also included, and the participants remembered treatments, such as massage and stretching, as being rough and painful.

About 1959 they thought that they could shorten the healthy leg to avoid my becoming lame, it failed so they had to operate again. They then damaged my left leg in the process.... [Man I; <4 years at onset of polio; < 26 years of late effects of polio]

I had to re-learn how to walk. I could walk when I was one year old, but I had to practice and re-learn. I went to a physio, a very strict and very rough woman. It was early in the morning. There were no wheelchairs for children in those days, instead you sat in a plaited, creaking basket with wheels. You had shortwave-treatment by attaching some sort of electrode, which stretched the legs out. You even got massage. I went to see her for

quite a long time, until I was old enough to go to primary school. [Man J; <4 years at onset of polio; <26 years of late effects of polio]

Orthoses to facilitate mobility

As children, they were given several orthoses to facilitate walking and other physical activities. They wore custom made and especially adjusted shoes, such as having higher heels to compensate for differences in leg lengths. These were heavy and made it difficult to run. Those who's feet differed in size had to make the shoe on the smaller foot fit, by filling the gap with cotton wool or a similar material. Orthoses and braces were prescribed for those with paralyzes of the legs and feet, and corsets for those who had problems in stabilizing the trunk and core muscles.

When I was a child, there was seven centimetres difference between the right and left leg. In those days, you were given a custom made shoe with a seven centimetres high heel... and it weighed tons. You often fell over whilst running. The foot gave way and then you stumbled and fell over right away. But when you're small and young... I don't know... somehow you compensated for it.... [Man H; <4 years at onset of polio; <26 years of late effects of polio]

It was rather tough for me as a teenager, since I had to fill one shoe with cotton wool or something similar to make it fit my foot better ... after I was twelve years old I've had heel cushions. Then they changed that and put the heel raiser straight onto my shoe. That's something I've always been grateful for.... [Woman C; >4 years at onset of polio; >26 years of late effects of polio]

Managing social encounters and living up to the expectations of others

Due to impairments, the participants were not able to keep up with their peers in physical activities. They felt alienated and stood out as being different, which often resulted in comments on their shortcomings. Adults expected them to take care of themselves and to manage on their own.

Alienation due to activity limitations

When school started, some were exempted from physical training, others joined in if things were manageable, but running was a

problem for everyone. Not being able to run meant that the participants avoided activities such as football and rounders. That meant that they had fewer chances to play and be with friends, especially as such activities often took place after school. Because of their impairments, almost everyone got the lowest grades throughout their school years in physical training. There was one exception among the participants, the one who had a PT teacher who disregarded the impairments and gave higher grades because of the effort and hard work that was put in.

... of course I was very cocky when I learned to balance and could manage the bar even if it was set really high up, and I've climbed and slithered on wall bars and ropes and things like that, so it I was determined to do it and I did. [Woman E; >4 years at onset of polio; <26 years of late effects of polio]

It was a bit tough to grow up with this.... It was tougher during primary school when a onetime military serviceman was the PT teacher. He would say "If you can run round the track in a certain time then I'll give you this grade". I couldn't run and therefore I always got the lowest grade. That's how it was... When I started high school I had a PT teacher who noticed that I took part in all the lessons and that I tried to manage all the things that were planned. Not like some of my classmates who, according to him, spent their time in coffeehouses and skipped the lessons. That's how I got grade 3 in physical training... [Man H; <4 years at onset of polio; <26 years of late effects of polio]

Feeling looked upon as different

Growing up with a physical disability following polio also meant that the participants drew a lot of attention to themselves. In their younger days, they felt that it was shameful to have impairments and to be "crippled." They were stared at and slowly became filled with a sense of being less worthy. They frequently had to explain why they were limping or were wearing braces. However, later on in life the participants found that people met them with more respect.

A lot is most likely related to my childhood and growing up. In my generation, for those of us who caught polio when we were growing up... it was a bit shameful. It wasn't really accepted that you were crippled as they called it back then. [Man H; <4 years at onset of polio; <26 years of late effects of polio]

... when I was a teenager I could sense a little bit of how you would be looked at as a handicapped person. But as the years have gone by these problems have disappeared. I'm not at all worried about using aids, well, I quite simply don't feel bad about it. Instead I feel that I'm accepted as an ordinary person despite my aids, if you know what I mean. [Man O; <4 years at onset of polio; <26 years of late effects of polio]

Meeting peers and making friends

Meeting people of similar age and making friends was not easy. The participants remembered being teased, bullied, and seldom invited to social events. It was a bit daunting at first, especially when they started to take interest in the opposite sex. However, almost all have at some time, been accepted for who they are, which was positive.

Well, as a young person, when you started to get in touch with the opposite sex you felt worried, if you know what I mean, because you're disabled. But it's worked out fine, it's gone well. And you know, I've just felt accepted despite my disability. They disregard my handicap so to speak, it's not a problem. [Man O; <4 years at onset of polio; <26 years of late effects of polio]

Managing a situation without complaining

According to the participants, they were not considered needing any specific help to manage, as people in general looked at their impairments following polio as nothing special. They were

expected to manage just like all the other children and not make a fuss.

But now as it were, I had quite a distance to get to school, you know, and I was the only one living in that area, so I had to walk. And then once I remember that when I had come down to the village, I fell over. ... and I had to crawl to a sort of fence, which I could hold on to and pull myself up. And then, then everything went well. [Woman G; >4 years at onset of polio; >26 years of late effects of polio]

... when I got polio, as a child you're expected to take care of yourself. You never had any rehabilitation... It didn't exist... If you got polio, then you had to learn to manage it. You accepted that... and we're probably the most agreeable of patients and one of those who'd tolerate most things. [Man I; <4 years at onset of polio; <26 years of late effects of polio]

Various psychological strategies for adapting

Growing up in an environment that was often tough and unfriendly required strategies to mitigate emotional reactions and to improve self-esteem. It was not only important to blend in with their peers, but the participants also had to prove that they could manage just as well or even better than they could. Some psychological strategies for adapting were trying to blend in, choosing to focus on the positive aspects of life, building a self-image, and trusting in their ability to manage.

Trying to blend in

The participants remembered how important it was to blend in and not to stand out as being different. They struggled to overcome or hide their disabilities and to adapt to whatever their peers were doing, even if it sometimes could be extremely painful. It was important to show other people that they were just as good as they were or even better.

Well, so all the time... it was like you had to assert yourself. Prove that you weren't an inferior person I think. [Woman F; <4 years at onset of polio; <26 years of late effects of polio]

Choosing to focus on positive aspects of life

Another strategy was to focus on the positive aspects of life. Activities that were out of reach were looked down upon as insignificant and unimportant, for example sporting activities. Other strategies were, being persistent, belittling the effects of polio, comparing themselves to healthy people, avoiding looking at the negative aspects of the situation, and focusing on what they had achieved.

But it wasn't a big problem, I'm not interested in sports anyway. Maybe I would have been if my legs had been healthy, there's no telling what might have been for certain... [Man L; <4 years at onset of polio; <26 years of late effects of polio]

Polio didn't affect me very much... the entire left side was affected when I fell ill at the age of four... and then after that the leg stopped growing so that one foot was quite a bit smaller than the other... But, well, things have been fine... [Man L; <4 years at onset of polio; <26 years of late effects of polio]

Building a self-image and trust in the ability to manage

The participants described that being forced to look after themselves, as was expected by other people, for example parents, teachers, and peers, brought about a conviction that if they really put their minds to it and had the energy to accomplish something, they could succeed. Because they always had to struggle to overcome difficulties, they became fighters, stubborn, and not

likely to give up. Gradually, they were building self-confidence and self-esteem.

... I'm pretty damn stubborn so it's. ... I don't give up easily, I can tell you that. I don't give... I don't give up, I finish what I set out to do. [Man L; <4 years at onset of polio; <26 years of late effects of polio]

... But then it... I mean, we've always said that all of us polio patients, we've never been ones who give up, and you know... we've always been fighting, you know ... [Woman G; >4 years at onset of polio; >26 years of late effects of polio]

Discussion

The main findings in the present study were the participants' first memories and reactions to falling ill, being immobilized, and needing treatment. Due to their impairments, they were not able to keep up with their peers in physical activities. Growing up in a tough and unfriendly social context required psychological strategies such as trying to blend in, focusing on the positive aspects of life, building one's self-image, and trusting in one's ability to manage.

The early childhood experiences were in line with previous studies in that the participants experienced different degrees of paralysis following the initial flu-like symptoms. Those who were very young at that time had blurry memories of the acute phase, but all recalled that they were unable to move, which caused feelings of fear and loss of control [18]. They were sent away from home, which was an unsettling experience, and they remembered that they felt sorry for their parents and relatives [19,26]. Such projections of their own sadness and fear of being on their own without their parents to support them may have forced them to become compliant and "good" as they were dependent on the hospital staff and expected to cooperate fully [18–20,26]. These attitudes, being obedient, polite, and showing tolerance and acceptance were still present among our participants.

To compensate for the physical impairments, the participants were fitted with different kinds of orthoses that they experienced as being cumbersome. When they returned to their homes, these devices drew a lot of unwanted attention, which made them feel uncomfortable. As they grew up, some were no longer dependent on their braces or other orthotic devices, which they felt was a relief. The participants said that the braces contributed in causing social stigma and were therefore regarded as symbols of disability [26].

Being looked upon as different subjected the participants to various kinds of bullying, which has been previously reported for children with childhood disability [27]. Disabled children run a considerably higher risk of being bullied than their able-bodied peers. Younger boys are more subjected to physical bullying than girls and adolescents, who are more frequently exposed to verbal or relational bullying aimed at excluding them from the group [27]. This was also reported among our participants. To be subjected to bullying may have psychological consequences, such as emotional instability and loss of self-esteem, which has also been reported among children with cerebral palsy (CP) and juvenile rheumatoid arthritis (JRA) [28–30]. In addition to the physical disability, the psychological reactions to bullying may make the children give up sports and leisure activities [29], as reported in our study. The perceived vulnerability when growing up with disabilities and the challenges encountered may have fostered their will to prove themselves worthy and the need to blend in, which were important adaptive strategies.

The narratives of our participants were in agreement with previous studies in that they thought that past treatments were mainly focused on the body and improving functioning, which overshadowed that of psychological and social development [26,28,31]. Their rehabilitation focused on physical treatments aimed at learning as many skills as possible, especially that of being able to walk [18,26] and increasing the ability to live independently to minimize the stigma of being disabled [18,19,26]. Focusing on physical aspects and learning how to walk are equally common today and have also been reported by persons growing up with CP [28]. It has been shown that physical health problems in early childhood can affect educational achievement, employment, marital status, and social relationships later in life. However, it is also important to face the psychological reactions that may arise when being disabled. Low self-esteem may later develop into depression and anxiety in people with a chronic illness contracted during childhood [32].

A previous study has reported that persons with polio were encouraged to "put the past behind them" which may have supported strategies such as denial and minimization that were also present in the narratives of our participants [20]. However, such strategies do not generate the necessary energy to pursue achievable goals. When designing individually tailored rehabilitation interventions, the findings in our study suggest that it may be important to address experiences from the past, including the emotional and psychological reactions that relate to the disability. This was also confirmed by a previous study showing how previous experiences of pain, paralysis, and fear may appear as "embodied memories," which may be expressed as depression, worries, and difficulties maintaining social relationships [33]. Strategies that were developed early may be made more constructive and purposeful when included in future rehabilitation programs. In a previous study of late effects of polio, we found that strategies, such as optimistic thinking, practical solutions, and social comparisons, were useful when the participants had grown older and their functioning had declined [9]. These strategies were the same as the participants used in their childhood. Certain strategies, however, were not functioning anymore; they are those that made the participants push themselves too hard, for example overachieving, disregard for pain, and weariness. It is therefore important to focus not only on physical functioning but also on psychological and social strategies. Future rehabilitation programs ought to include experiences from the past in order to provide person-centered, interdisciplinary interventions.

Methodological considerations

The fourteen participants showed a wide range regarding age and clinical symptoms. They were strategically selected and were considered mildly to moderately affected and can therefore be regarded as representative of most, albeit not all persons with late effects of polio. The participants provided plentiful and diverse data and improved our understanding of what it meant to grow up following paralytic polio.

With regard to reflexivity, we are aware that our pre-understanding as clinicians and researchers could affect the quality of the data and create a possible bias [34]. Therefore, all authors worked separately during the initial process of generating meaning units and constructing codes. We, as authors, continually discussed the results during the analysis in order to remain neutral and to eliminate possible influences of previous experiences. Systematic text condensation is useful for analysis of meaning and content of data across cases and was therefore chosen as the

procedure to facilitate cross-case synthesis among the participants. We have shown the representation of each participant by assigning a code with gender, a capital letter (i.e., a fictitious name) and age, above or below the mean of 4 years, when contracting polio, and the duration of late effect of polio (i.e., above or below the mean of 26 years) after each quotation, in order to add transparency and trustworthiness to our findings and interpretations of the data.

Some data could have been affected by the retrospective study design. Yet, when the participants responded to how they had experienced their childhood and adolescence, they presented such detailed memories that included emotional reactions even at the time of the interview. This intense memory suggests that these recollections most likely have had a considerable impact on their lives, as shown in previous studies [8,9,18,19,22,23,26].

Conclusions

Growing up with a disability after paralytic poliomyelitis presented both physical and psychological challenges, necessitating new strategies for managing daily situations, such as optimistic thinking, trying to blend in and trust in one's ability to manage. At the onset of late effects of polio, some of these strategies were still functioning. Strategies that were obsolete were those that made the participants work too hard, for example overachieving, disregarding pain, and weariness. By understanding the experiences and evolved strategies from the past, rehabilitation professionals may better support persons with late effects of polio in their process of adaptation to the new situation.

Acknowledgments

The authors wish to thank all participants for their cooperation and Mr. James Suckling for linguistic review of the manuscript.

Disclosure statement

The authors declare no conflict of interest.

Availability of data and materials

All relevant data are presented in the manuscript. Our raw data are coded, and the key is only available to the responsible researchers. The Regional Ethical Review Board in Lund has not given permission to anyone else to access the data. Please contact the corresponding author Catharina Sjö Dahl Hammarlund, who can give more information, if requested, concerning the background of results.

Funding

The study was supported by the Gyllenstierna Krapperup Foundation, Sweden, Stiftelsen för bistånd åt rörelsehindrade i Skåne, Sweden, the Department of Health Sciences at Lund University, Lund, Sweden, and the Faculty of Medicine at Lund University, Lund, Sweden.

ORCID

Catharina Sjö Dahl Hammarlund  <http://orcid.org/0000-0001-6071-6922>

Jan Lexell  <http://orcid.org/0000-0001-5294-3332>

Christina Brogårdh  <http://orcid.org/0000-0002-9249-9421>

References

- [1] Lexell J. Postpoliomyelitis Syndrome. In: Frontera W, Silver J, Rizzo J, editors. *Essentials of physical medicine and rehabilitation*. 3rd ed. Philadelphia: Elsevier Saunders; 2014. p. 775–781.
- [2] Farbu E, Gilhus NE, Barnes MP, et al. EFNS guideline on diagnosis and management of post-polio syndrome. Report of an EFNS task force. *Eur J Neurol*. 2006;13:795–801.
- [3] Jensen MP, Alschuler KN, Smith AE, et al. Pain and fatigue in persons with postpolio syndrome: independent effects on functioning. *Arch Phys Med Rehabil*. 2011; 92: 1796–1801.
- [4] Koh ESC, Williams AJ, Povlsen B. Upper-limb pain in long-term poliomyelitis. *Quarterly J Med*. 2002;95:389–395.
- [5] Murray D, Hardiman O, Meldrum D. Assessment of subjective and motor fatigue in Polio survivors, attending a Postpolio clinic, comparison with healthy controls and an exploration of clinical correlates. *Physiother Theor Pract*. 2014;30:229–235.
- [6] Trojan DA, Cashman NR. Post-poliomyelitis syndrome. *Muscle Nerve*. 2005;31:6–19.
- [7] Brogårdh C, Lexell J, Lundgren-Nilsson A. Construct validity of a new rating scale for self-reported impairments in persons with late effects of polio. *PM & R: J Injury Funct Rehabil*. 2013;5:176–181.
- [8] Brogårdh C, Lexell J, Sjö Dahl Hammarlund C. Experiences of falls and strategies to manage the consequences of falls in persons with late effects of polio: a qualitative study. *J Rehabil Med*. 2017;49:652–658.
- [9] Sjö Dahl Hammarlund C, Lexell J, Brogårdh C. Perceived consequences of ageing with late effects of polio and strategies for managing daily life: a qualitative study. *BMC Geriatr*. 2017;17:179.
- [10] Winberg C, Carlsson G, Brogårdh C, et al. The perception of physical activity in ambulatory persons with late effects of polio: a qualitative study. *J Aging Phys Act*. 2016;24:1–26.
- [11] Winberg C, Flansbjerg U-B, Carlsson G, et al. Physical activity in persons with late effects of polio: a descriptive study. *Disabil Health J*. 2014;7:302–308.
- [12] Brogårdh C, Lexell J. Falls, fear of falling, self-reported impairments, and walking limitations in persons with late effects of polio. *PM & R: J Injury Funct Rehabil*. 2014;6: 900–907.
- [13] Brogårdh C, Lexell J. How various self-reported impairments influence walking ability in persons with late effects of polio. *Neuro Rehab*. 2015;37:291–298.
- [14] Larsson Lund M, Lexell J. Relationship between participation in life situations and life satisfaction in persons with late effects of polio. *Disabil Rehabil*. 2009;31:1592–1597.
- [15] Lexell J, Brogårdh C. Life satisfaction and self-reported impairments in persons with late effects of polio. *Ann Phys Rehabil Med*. 2012;55:577–589.
- [16] Larsson Lund M, Lexell J. A positive turning point in life-how persons with late effects of polio experience the influence of an interdisciplinary rehabilitation programme. *J Rehabil Med*. 2010;42:559–565.
- [17] Griffin JM, Hawke WA, Barraclough WW. Mental hygiene in an orthopedic hospital. *J Pediatr*. 1938;13:75–85.
- [18] Bruno RL, Frick NM. The psychology of polio as prelude to post-polio sequelae: behavior modification and psychotherapy. *Orthopedics*. 1991;14:1185–1193.

- [19] Hollingsworth L, Didelot MJ, Levington C. Post-polio syndrome: psychological adjustment to disability. *Issues Ment Health Nurs.* 2002;23:135–156.
- [20] Scheer J, Luborsky ML. The cultural context of polio biographies. *Orthopedics.* 1991;14:1173–1181.
- [21] Meyer E. Psychological considerations in a group of children with poliomyelitis. *J Pediatr.* 1947;31:34–48.
- [22] Ahlström G, Karlsson U. Disability and quality of life in individuals with postpolio syndrome. *Disability Rehabil.* 2000;22:416–422.
- [23] Wenneberg S, Ahlström G. Illness narratives of persons with post-polio syndrome. *J Adv Nurs.* 2000;32:354–361.
- [24] Malterud K. Systematic text condensation: a strategy for qualitative analysis. *Scand J Public Health.* 2012;40:795–805.
- [25] Patton MQ. *Qualitative evaluation and research methods.* Thousand Oaks: Sage Publications Inc.; 2002.
- [26] Harrison TC, Stuijbergen A. A hermeneutic phenomenological analysis of aging with a childhood onset disability. *Health Care Women Int.* 2005;26:731–747.
- [27] Chatzitheochari S, Parsons S, Platt L. Doubly disadvantaged? Bullying experiences among disabled children and young people in England. *Sociology.* 2016;50:695–713.
- [28] Moll LR, Cott CA. The paradox of normalization through rehabilitation: growing up and growing older with cerebral palsy. *Disability Rehabil.* 2013;35:1276–1283.
- [29] Russo E, Trevisi E, Zulian F, et al. Psychological profile in children and adolescents with severe course Juvenile Idiopathic Arthritis. *Sci World J.* 2012;2012:1.
- [30] Verstappen SM, Cobb J, Foster HE, et al. The association between low socioeconomic status with high physical limitations and low illness self-perception in patients with Juvenile Idiopathic Arthritis: results from the childhood arthritis prospective study. *Arthritis Care Res.* 2015;67:382–389.
- [31] Harrison TC. A qualitative analysis of the meaning of aging for women with disabilities with policy implications. *ANS Adv Nurs Sci.* 2006;29:E1–E13.
- [32] Gledhill J, Rangel L, Garralda E. Surviving chronic physical illness: psychosocial outcome in adult life. *Arch Dis Child.* 2000;83:104–110.
- [33] Leuzinger-Bohleber M. Biographical truths and their clinical consequences: Understanding ‘embodied memories’ in a third psychoanalysis with a traumatized patient recovered from severe poliomyelitis. *Int J Psycho-Anal.* 2008;89:1165–1187.
- [34] Malterud K. Qualitative research: standards, challenges, and guidelines. *The Lancet.* 2001;358:483–488.