**Polio Survivors Perceptions of a Multi-Disciplinary Rehabilitation Programme.**

Purpose: Post-Polio Syndrome refers to a late complication of the poliovirus infection. Management of post-polio syndrome is complex due to the extensive symptomology. European and UK guidelines have advised the use of rehabilitation programmes to manage post-polio syndrome. There is limited a paucity of research in relation to the effectiveness of rehabilitation interventions. The objective of this study is toexplore polio survivor’s perceptions of an in-patient multi-disciplinary rehabilitation programme.

Methods: Semi-structured interviews of community dwelling polio survivors who attended in-patient rehabilitation programme in the United Kingdom. Thematic analysis was used to describe and interpret interview data.

Results: Participants’ experiences were influenced by past experiences of polio and their self-concept. Participants generally had a positive experience and valued being with other polio survivors. Positive strategies such as pacing and reflection changed their mind-sets into their lives after the programme, though they still faced challenges in daily living. Some participants supported others with post-polio syndrome after completing the programme.

Conclusion: Our research identified that participants experienced long term positive benefits from attending a rehabilitation programme. Strategies that users found helpful that explored the effectiveness of interventions to manage polio are not cited within a Cochrane review. If we are to recognise the lived experience and service user empowerment within a model of co- production it is essential that patient preferences are evaluated and used as evidence to justify service provision. Further research is required with polio survivors to explore how best rehabilitation programmes can adopt th**e** principles of co-production.

# 

Key words: Co-production, self- management, self-concept, pacing, post-polio syndrome, coping strategies.

**Introduction.**

A significant achievement of world health policy has been the elimination of polio in many countries. However, disability related to polio continues amongst polio survivors. Post-Polio Syndrome refers to a late complication of the poliovirus infection where new health problems or the exacerbation of existing symptoms occur [1]. The prevalence of post-polio syndrome affecting previous polio patients has been reported to be between 20-85% [2,3]. The major clinical features of post-polio syndrome include progressive muscle weakness, increased muscle atrophy, abnormal muscle fatigue, generalised fatigue, muscle and joint pain, muscle cramps and cold intolerance [4, 5]. Symptoms of post-polio syndrome often affect an individual’s performance of activities of daily living such as bathing, dressing, cooking and housework as well as walking and climbing stairs [5]. Adaptation can be a difficult process which involves strategies to cope with negative symptoms and reduced capabilities [6].

With no curative treatment for post-polio syndrome national and international guidelines focus on the management of the condition (7, 8). A wide range of multi-disciplinary team treatments are recommended, including exercise, diet management, patient education, assistive technology and lifestyle modifications. Interestingly a Cochrane Review [9] concluded that there is insufficient evidence of effectiveness of non-pharmacological interventions. The review excluded all quantitative studies below level 1 and qualitative studies. Current guidelines additionally describe the benefits of attending a group multidisciplinary programme [7]. However the Cochrane review was critical of the study by Strumese [10] that examined the effectiveness of a post-polio rehabilitation programme and excluded the study by Davidson et al [11] due to methodological concerns. In this study the authors suggest significant improvements were reported in levels of fatigue, depression and in exercise endurance but not muscle strength and anxiety. Additionally there is a paucity of research that has examined user perceptions of programmes. Two Swedish studies were identified in the literature search that evaluated the experience of an interdisciplinary rehabilitation programmes from a user perspective [12,13] . The respondents in this study expressed feeling supported in a process of positive change that lead to increased self-awareness and hope, increased understanding of the condition and appropriate coping strategies as well as acceptance of life with post-polio syndrome.

With a paucity of research in relation to user perceptions of rehabilitation programmes there is a need to ascertain user perceptions particularly if services are to support the values of collaborative co–production. This means focused around the service user’s needs, values, and preferences [14]. The aim of this study was to explore the user perspective of a post-polio rehabilitation programme to enhance service delivery.

**Methodology**

Qualitative interviews were carried out to ascertain from the user perspective their experience of attending a multi-disciplinary group rehabilitation programme. Telephone interviews are often compared to face-to-face interviews in relation to their ability to enable rich data collection [15, 15). Additionally they allow for data to be collected across a wide geographical region [17]. This was particularly important as it was hoped it would allow more polio survivors to participate due to mobility limitations and or transport restraints. The anonymity that a telephone interview can offer can be preferable in discussion of sensitive topics [15, 18]

Telephone interviews are able to collect rich data [15, 16] although telephone interviews can lose valuable data without visual cues gathered from face-to-face interviews [19]. The researcher using telephone interviews needs to be highly skilled, so as to be more sensitive to the interviewee’s voice, as they can’t pick up on body language or facial expressions that might indicate that the respondent is distressed, in discomfort or is taking time to think [20]. However there are still non-verbal clues that the researcher can use such as sighs and hesitations though it should be acknowledged that these too could be misinterpreted [19, 20].

Whilst these studies examine particular populations and topics, it is hard to say how preferable a telephone versus face-to-face interview might be for people with post-post syndrome or whether a universal preference even exists as individuals may have personal preferences. However by being explicit regarding the topics covered in the research and offering a face-to-face as well as a telephoneinterview, it was hoped that participants could opt for a method they felt most comfortable with. All interviews were recorded.

Participants were invited to take part in the research through an article in the bi monthly Bulletin magazine. All participants were asked to contact the key informant and asked for permission to forward their details to the researchers. A snowball sampling technique was adopted in which participants were also invited to recruit participants from their own networks. The inclusion criteria were that participants had to have previously attended a post-polio multidisciplinary, rehabilitation programme. Sixteen polio survivors replied to the invite with a further 4 people contactingthe researchers through snowballing sampling. Two persons were not eligible for inclusion, as they had not attended a rehabilitation programme. Of the 14 who volunteered and were eligible for the study, 10 consented to taking part and were interviewed. Eight telephones interviews and two face-to-face interviews were carried out. Ethical approval was obtained from a university ethics committee. The interview questions are outlined in Table 1

Table 1

The design of the interview questions was informed from the literature and discussion with the key informant. Demographic information about the participant, their history of polio and post-polio syndrome and information about the rehabilitation programme they attended was collected (Table 2). In total 6 females and 4 males participated in the study. None of the participants identified themselves as white British with one identifying herself as white European. The mean age was 70. Most of the participated reported developing Post Polio symptoms ranged between 35 and 73 with 7 participants reporting symptoms in their early to mid-50s.

Table 2

The programmes participants’ attendance varied. One participant attended a 3-week individual MDT rehabilitation programme in a hospital setting and another attended an on-going, private weekly individual physiotherapy-led rehabilitation programme in a gym. The other eight participants attended the same 2-3 week residential group multidisciplinary rehabilitation programme in a hospital as outlined in table 3.

Table 3

Eight participants (Table 4) attended the same programme but in different years so the delivery of the programme and even content could have changed slightly.

Table 4

**Data Analysis**

The sample of 10 participants in this study corresponds with the recommended sample size for sufficient in-depth analysis in phenomenological research [21]. The first stage involved familiarising with the data. The researchers immersed themselves in the data until the researcher was familiar with the breadth and depth of the content. This involved transcribing audio recordings of the interviews verbatim, reading and rereading the transcripts. During this phase, initial interesting notes and ideas were marked down whilst the researcher was reading. The second stage involved generating initial codes. By working systematically through the transcripts, initial semantic and latent codes from the data were produced [22]. These codes identify a meaningful feature of the data regarding the phenomenon and found interesting by the researcher. It was endeavoured that equal attention should be given to each part of the data set during this process. A list was produced of all the codes identified in the data set. The third stage involved searching for themes. Codes were sorted into potential themes. Relevant coded data extracts were collated into their relevant themes. Themes were created by looking at the relationship between codes, then between themes and sub themes.  A taxonomy was used to classify and organise the information. The fourth stage involved reviewing themes whilst the fifth stage involved refining and defining the specifics of the themes and the identification of the essence of each theme

The two researchers collaborated during the analysis by check coding. An inter-subjectivity agreement was fixed at 80-95%, a recommended by Miles and Huberaman [23]. Three transcripts were then sent to a polio survivor who independently analysed the coding and transcript.

**Results**

*Accessing Support and the Programme*

All the participants with the exception of Paul and Susan reported problems accessing support with many of the participants actively looking for a rehabilitation programme (Daniel, Beth, Maria, Andrea, Tom). Most of the participants with the exception of Susan and Beth attended the programme looking for strategies to manage changes occurring in activities of daily living.

*‘I could strip a motorbike and rebuild it. But then gradually post-polio syndrome set in, you could do less and less.’* (David)

Admitting that your functioning had changed was difficult for many participants.

*‘You believe when you get post polio that you can do as much as you did previously with polio’* (Mark)

*‘I was at the stage where my old life was over. I couldn’t work anymore…I was at the stage where my life has no sense.’* (Maria)

All of the participants identified themselves as being strong-willed, driven, positive and or independent. Susan described how this had prevented her from attending the rehabilitation programme on first invitation. Some participants linked past experiences for their reluctance to ask for help.

*‘ Never tell anybody how you feel; Never cry in front of your parents, because they will get even more upset…, no matter how bad you feel, say ‘I am absolutely fine thank you… And so how are health professionals meant to understand how I am feeling if I lie to them all the time?’ (Paul)*

For Susan and Maria, memories of past treatment impacted their feelings about attending the programme.

*‘I was dreading it, because of the reminder of earlier experiences as a child, of being hospitalised and going to rehab.’ (Maria)*

Andrea described how the coping strategies as a polio survivor in the past differed from those suggested in the programme. Some of the participants perceived that it was important for the programme to support them to start asking for help when needed (Susan, Paul and Daniel).

*Being on the programme*

The programmes were led either by a physiotherapist and or an occupational therapist. All but one of the participants responded positively about the programme describing the programmes as ‘remarkable’, ‘enlightening’ and ‘interesting’, however Susan said that parts of the programme didn't resonate with her. Expertise and experience of the professionals who taught on the programme was particularly valued by the participants. Paul and Beth valued the opportunity to ask questions throughout the programme whilst Tom and Mark spoke about the lack of awareness and experience of post-polio syndrome amongst health care professionals.

Participants talked about the advice and strategies on the programmes. Hydrotherapy was well received by all of the participants who experienced it on the programme. Susan felt that the programme she attended didn't provide any advice on alternative or complementary therapies other than hydrotherapy. Maria suggested that the Cognitive Behaviour Therapy sessions should be practical rather than theoretical as that would be more applicable to the participant’s lives. Susan felt that the psychological aspect of post-polio syndrome was not addressed enough on the programme she attended, whereas Mark and Andrea perceived that the psychological sessions were not relevant for them*.* Andrea and Susan felt practical sessions to try things out for themselves were important, so were disappointed when a catalogue was used to show participants assistive devices. Andrea, Mark and Susan also emphasized the need for individual assessment and support.

Susan explained that the programme didn't resonate with her as the health care professionals weren’t able to address her needs.

*‘They didn’t address upper body at all…. their thought was ‘strap my shoulder up and my arm’ , I nearly burst into tears cause it was limiting me even more.’ (Susan*)

Andrea perceived that the strategies that the occupational therapist had suggested to manage her shopping without listening to why this would not work for her. Daniel also mentioned how a disagreement with one of the doctors on the course had stuck with him.

All of the participants felt that being with other people with post polio syndrome was an important aspect of the programme. Six participants also spoke about the revelation of meeting others with polio having been isolated from one another before. Paul suggested this had a role in the group dynamics:

*‘So once I got on this course…I was shy and embarrassed and didn’t know what to expect. And there were 5 other people in exactly in the same position…. All polio victims: All who’ve said that they haven’t actually come across... many polio victims. So immediately we were all kindred spirits’*

Jessica, Susan and Andrea felt that the rehabilitation programmes gave them time to reflect Susan stated it have her *‘the time to think about how I would adjust my life’.* Similarly, Jessica described the rehabilitation programme as providing the opportunity *to: ‘focus on oneself and not feel guilty’*

*Life since the programme*

Most of the participants talked about the outcomes of the programmes and how it had enhanced their quality of life. Mark summarized his experience saying:

*‘I just couldn’t believe, how much of a difference it had made to the quality of my life so as simple as that.*

For Jill, Mark and Tom pacing was something not considered or been aware of before*.* For Maria is gave her permission change her ‘rh*ythm’.* Paul reported that being told to stop if tired allowed him to change his old ways.For Beth the programme enabled her to better understand her body and when to rest. Both Tom and Ann spoke of the benefits from pacing, being able to continue activities they enjoyed without ending up, as Tom described ‘*flat on my back’* Most of the participants reflected that the programme supported them to communicate with others. For Paul and Susan this meant changing their mind-set so they could admit they couldn’t do something without *‘shame’ .*

Maria and Beth felt they could better explain how they felt after the programmes. Maria spoke about communicating with family. Whilst Susan felt that there was still progress to be made before her family could understand her, Paul felt that the techniques had not only supported his family to understand his situation but also his GP, saying:

*‘I was then able to, to talk to…. my own GP, who never even heard of post polio syndrome- So I was able to put him right.’ (Paul)*

The other outcomes of the programme varied amongst participants Mark reported he’d lost weight and Andrea said she’d maintained her independence, compensating using assistive devices. Jessica also reported she’d maintained independence, staying at work. Jessica also spoke about the benefits of the exercise alongside Paul and Beth: For Jessica she felt this had reduced her need for analgesics, whereas Beth and Paul felt more energised after exercise.

*On-going challenges*

Despite all participants reporting successfully incorporating some strategies into their daily life they also described on going challenges in their life since the programme. Susan, Jill, Anne, and Paul talked about the difficulties in adopting the strategies and advice from the programme. Having coped with a condition throughout their whole lives Susan and Paul described the difficulty of letting go of strategies that had previously protected them. External factors were articulated as preventing participants from meeting goals set in the programme. Several participants reported that they had moved house since the programme putting some of their goals, such as exercising to one side whilst busy. Tom described the logistical difficulties accessing a hydrotherapy pool and fitting this into his routine. Mark similarly pointed out the problems of accessing hydrotherapy on the NHS.

Comorbidities also posed a problem to some participants as they were managing more than the post- -polio syndrome and found it hard to know what to attribute to which condition in some cases and. Participants acknowledged changes and deterioration due to post-polio syndrome Andrea felt that she was no longer doing as well as she could and was concerned how she would manage after surgery on her shoulder. Beth spoke about difficulties she had with her posture and also becoming more breathless, something she’d noticed had improved in the rehabilitation programme. Daniel, Paul and Beth referred to the difficulties of managing fatigue. Daniel discussed the difficulties of maintaining the positive mind-set, he had developed since the course:

*‘I know what I can do and I just made sure that I pace myself. I mean sometimes it, it, gets you down. When you think ‘well bloody hell I used to be able- I can’t do that now’.*

Four of the participants reported having recommended the rehabilitation programme to others as they had found it so beneficial. However for Mark, contacting people with people with polio and post- polio syndrome was also a goal he wanted to achieve having being on the programme. Daniel felt it has been so important to share information with others who have post- polio syndrome. Beth also revealed that, not only did she volunteer for her local hospital, but also carried out a training session on post-polio syndrome for allied health care professionals, with the physiotherapist whom she was on the rehabilitation programme with. Paul also supports health care professionals by volunteering to be part of medical exams and doing this he has been able to continue learning about his condition. Jessica felt strongly about the need to support others with post-polio syndrome through contributing to research.

**Discussion**

This is the first paper in the United Kingdom to ascertain user experience of a post-polio rehabilitation programme. The management of post-polio syndrome is challenging to the multidisciplinary rehabilitation team [24]. Healthcare professionals need to learn about post- polio syndrome so that they can accurately assess an individual’s functional and health educational needs [5]. However our research has highlighted the need for professionals to listen to polio survivor’s unique experiences of polio and post-polio syndrome and how this may influence current and future rehabilitation strategies. Previous research has shown that polio survivors often had frightening experiences related to inpatient management of their condition [25]. In addition the advice to ‘*just get on with it’* and to ‘*fit in’* resulted in polio survivors developing strong personalities in order to be accepted into society [26]

In our study many of the participants actively sought a programme to manage the late effects of polio. In our study the participants did value the information they received in the programme as suggested by Yorkston and Johnson [27]. The success of the programme may be attributed to the fact that in our study most of the participants had a positive attitude. The notion of being positive has been deemed to be a key coping strategy although it could mask patients’ concerns and needs [28]. Lazarus and Folkman [28] theorise that problem solving and emotional regulation of behaviours are important in the coping process. In addition information seeking needed for problem solving and emotional regulation of behaviours could be interpreted as positive self-acceptance. Time to reflect was also valued by polio survivors. There is growing evidence of reflection as a tool to facilitate user’s behaviour within health care e.g. families experience of health [30], activity within pain management [31], obesity in the third age [32]

The variation, in the outcomes and the strategies adopted, may relate to the varied content of the programmes attended by our study’s participants. However the findings concur with Lexell and Lund’s [12] study that found, even when the same rehabilitation plan was applied in the same way, participants were empowered to adopt different changes to varying degrees. The reasons participants gave for why they had or hadn’t incorporated strategies into their daily living aligned with research suggesting strategies are selected based on personal goals, awareness of capabilities and environmental constraints [33]

Our findings support research from previous studies that found that polio survivors perceived a post-polio rehabilitation programme had positive benefits [11,12,13]. Hydrotherapy was valued as an intervention even though a Cochrane review on the management of polio syndrome treatment concluded there is only low-level evidence that resistance training in the thumb can improve muscle strength [9]. In contrast supervised muscular training programmes and water exercises are recommended treatments according to European guideline [8].

Rehabilitation is the process that aims to enable people with functional limitations to reach and maintain their optimal physical, mental and social functional capabilities. It is often described as an active, time-limited collaboration with a team of professionals and other relevant people to reduce the impact of a condition on daily life [34]. Our research emphasises the importance of rehabilitation not being time-limited shown in our research by the participants reporting a gradual process of adopting strategies to manage post-polio syndrome. In particular there is a need to address and manage falls within this population. One study found that 45% reported to have had a fall with 23% having a fracture. Interestingly only leg-length discrepancy was a significant factor associated with falls among Korean polio survivors [35].

In addition there were considerable long-term advantages of attending a rehabilitation programme. Indeed the establishing of new behaviours is essential for rehabilitation programmes [36]. Previous studies only examined rehabilitation programmes after 12 weeks [13], 6 months [11] and between 9-12 months [12]. Thus there is a need to consider the long term value of rehabilitation programmes. What was evident is the need for support to manage not only co-morbidities associated with ageing but to manage new and or unresolved issues such as fatigue. Fatigue and pain are often the most frequent complaints of post-polio syndrome [9].

Compliance with interventions remains a challenge for healthcare professionals and requires a combination of different strategies including simplifying treatment regimes; ensuing patients understand information and strategies to modify beliefs and human behaviour such as life style design [36]. Though the strategies participants adopted varied, all the participants in our study highlighted pacing activities were an important strategy they had taken from the programme. Despite limited evidence to support pacing it has been recognised as an important coping strategy [6]

The participant’s relationship with therapists appeared to influence their experiences of the programme as suggested by Larson, Lund and Lexell [12]. There was evidence that professionals need to listen to polio survivors current coping strategies. Polio survivors in Atwal et al [37] were critical of health and social care professionals for not listening to their needs and often dismissing their concerns. Listening skills are highly valued by service users. One study found that patients are prepared to wait longer for an appointment to see a General Practioner who had good listening skills [38].

In our study polio survivors perceived that peer support was important as suggested by Larson Lund and Lexell [12]. According to the Santos-Tavares and Thoren-Jonnson study [39] participants felt a need to meet others with post-polio syndrome and felt that they had a mutual understanding amongst one another due to their similarity. The findings of our study found that some participants, having attended the programme, sought to help other, either directly or through supporting health care professionals. This has not been recognised in the polio literature but delivering services which are based upon effective information exchange and shared decision making are the foundations of co-production. Moreover users often want to get involved with and or ‘give something’ back as part of their own recovery and or rehabilitation [40].Co-production should be used as a future model in which rehabilitation support services and programmes are ran in partnership with polio survivors as opposed for polio survivors. Indeed Lexell et al [41] found that those who were mutually involved in their rehabilitation process were actively engaged.

Limitations

As based on interview data the present study can only report the changes participants reported the programme to have made on lives rather than the actual impacts. 10 participants volunteered to take part in the research making to difficult to ensure data saturation was reached. Data saturation is widely adopted in qualitative research to justify sample size, though more commonly with grounded theory research [42]. A large sample size does not guarantee saturation if the data collected is not rich in its quality [43]. Although no new themes or codes were generated when analysing the final transcripts it was difficult to tell if saturation had been reached due to the homogeneity of the sample.

Although some aspects of the programme appeared to have an influence on the participants’ experiences it was not clear in the present study which aspect of the programme led to the positive changes in participants' mind-sets. Some participants may have started to adapt and develop coping strategies before attending the programme

Volunteer bias may have lead to findings relating to participants giving something back as participants who volunteer for research are more likely to be actively involved in these occupations. It would have been useful to gather information on the occupations, home situation and marital status of the participants to inform greater interpretation of the findings. Interestingly the gatekeeper who received the requests for more information about the research was approached by several people who had not been able to attend a programme but wanted to tell their story about their experience of lack of healthcare support for post-polio syndrome. This indicates there is demand within the community for further research to understand the experiences of people with post-post syndrome.

**Conclusion**

This study offers new insights into the experiences of participants on rehabilitation programmes. The importance of pacing as a strategy and reflection was emphasised by participants attending the programme. This study also found that, having attended the programme, participants used their knowledge to support others as well as sharing their knowledge with health care professionals. The benefits of the programme were therefore found to extend further than just the participants who attended. In particular there is a need to explore how theories underpinning co production can be used to underpin rehabilitation services. Our research has highlighted the importance of peer support and the wish to ‘give something back’ which are important outcomes of co production.

**References**

1. Gonzalez H, Olsson, T, Borg, K. Management of post polio syndrome. Lancet Neurol 2010; 9: 634-642.

2. Julbert,B., and Agre, J.C . Characteristics and Management of postpolio syndrome. JAMA 2000; 284: 412-414.

3. Trojan, D.A., and Cashman, N.R. Post-poliomyelitis syndrome Muscle Nerve 2005; 1: 6-19.

4. Larsson Lund, M., and Lexell, J. Associations between perceptions of environmental barriers and participation in persons with late effects of polio. Scand J Occup Ther 2009; 16, 194-204.

5. [Atwal A](https://www.ncbi.nlm.nih.gov/pubmed/?term=Atwal%20A%5BAuthor%5D&cauthor=true&cauthor_uid=22816389), [Giles A](https://www.ncbi.nlm.nih.gov/pubmed/?term=Giles%20A%5BAuthor%5D&cauthor=true&cauthor_uid=22816389), [Spiliotopoulou G](https://www.ncbi.nlm.nih.gov/pubmed/?term=Spiliotopoulou%20G%5BAuthor%5D&cauthor=true&cauthor_uid=22816389), [Plastow N](https://www.ncbi.nlm.nih.gov/pubmed/?term=Plastow%20N%5BAuthor%5D&cauthor=true&cauthor_uid=22816389), [Wilson L](https://www.ncbi.nlm.nih.gov/pubmed/?term=Wilson%20L%5BAuthor%5D&cauthor=true&cauthor_uid=22816389). Living with polio and postpolio syndrome in the United Kingdom Scand J Occup Ther 2013; 27: 238-45.

6. Atwal, A., Spiliotopoulou, G., Coleman, C., Harding, K., Quirke, C., Smith, N., Osserain, Z., Plastow, N., and Wilson, L. Polio survivors’ perceptions of the meaning of quality of life and strategies used to promote participation in everyday activities, Health Expect 2014; 1-12

7. British Polio Fellowship Post Polio Syndrome. A guide to management for health care professionals 2014. Available at.http://www.britishpolio.org.uk/polio-and-post-polio-syndrome/. Accessed on the 17/05/2017

8. Farbu E. Update on current and emerging treatment options for post-polio syndrome. Ther Clin Risk Mang, 2010; 6: 307-313.

9. Koopman, F.S., Uegaki, K., Gilhus, N.E., Beelen, A., de Visser, M., and Nollet, F Treatment for postpolio syndrome (Review) Cochrane Database Syst Rev 2011; 1- 60.

10. Strumse, Y.A.S., Stanghelle, J.K, Utne, L, Ahlvin, P, Svendsby, EK Treatment of patients with postpolio syndrome in a warm climate. Disabil Rehabil 2003; 25: 77-84.

11. Davidson C.A, Auyeung V, Luff R, Holland M, Hodgkiss A, Weinman, J. Prolonged benefit in post polio syndrome from comprehensive rehabilitation: A pilot study Disabil Rehabil 2009; 31: 309-317.

12 Larsson Lund, M., and 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.

13 Lexell, E.M., Lexell, J, Larsson-Lund, M. (2015) The rehabilitation plan can support clients active engagement and facilitate the process of change–experiences from people with late effects of polio participating in a rehabilitation programme Disabil Rehabil 2015 38: 1-8.

14 Atwal A Inter professional Collaborative Co-production: Challenges and Opportunities Nursing Times (in press)

15 Greenfield TK, Midanik LT, Rogers JD Effects of telephone versus face-to-face interview modes on reports of alcohol consumption. Addiction 2000; 95 ; 277-284

16 Waterman H, Leatherbarrow B , Slater, R. Postoperative pain, nausea and vomiting: Qualitative perspectives from telephone interviews . J Adv Nurs 1999; 29: 690-696

17. Thomas R and Purdon C Telephone methods for social surveys. Social Research Update 1999; University of Surrey. Guildford. Available at: <http://sru.soc.surrey.ac.uk/SRU8.html>. Accessed on the 17/05/ 2017

19. Sturges JE and Hanrahan KJ Comparing telephone and face-to-face qualitative interviewing: a research note. Qualitative Research 2004; 4: 107

20. Opdenakker R (2006) Advantages and Disadvantages of four interview techniques in qualitative research. Qualitative Social Research 2006;7:Art 11

21. Creswell J.W Qualitative Inquiry and Research Design Choosing Among Five Approaches. 2nd edn 2007; London United Kingdom. Sage Publications.

22. Boyatzis R.E. Transforming qualitative information: thematic analysis and code development 1998; London. United Kingdom. Sage Publications.

23 Miles MB, Huberman AM  Qualitative data analysis. Second Edition. 1994. Thousand Oaks. Sage Publication

24. Howard, R.S. Poliomyelitis and The Postpolio Syndrome BMJ 2005; 330: 1314-318.

25. Wenneberg, S. and Ahlstrӧm, G Illness narratives of persons with post- polio syndrome. J Adv Nurs 2000; 31: 354–361.

26. Ahlström, G. and Karlsson, Disability and quality of life in individuals with post polio syndrome. Disabil Rehabil 2000; 22: 416-422.

27. Yorkston KM; Johnson K;  Boesflug E;  Skala J, Amtmann D Communicating about the experience of pain and fatigue in disability Qual  Life Res  2010; 19; 243-

28. [Cameron J](https://www.ncbi.nlm.nih.gov/pubmed/?term=Cameron%20J%5BAuthor%5D&cauthor=true&cauthor_uid=24852028), [Waterworth S](https://www.ncbi.nlm.nih.gov/pubmed/?term=Waterworth%20S%5BAuthor%5D&cauthor=true&cauthor_uid=24852028).  Patients' experiences of ongoing palliative chemotherapy for metastatic colorectal cancer: a qualitative study. Int Palliat Nurs 2014; 20: 218-224

 29. Lazarus, RS, & Folkman S.[Stress, appraisal, and coping](https://ccme.osu.edu/WebCastsFiles/562The%20Management%20of%20Stress%20-%202.pdf) 1984; New York: Springer.

 30. [Smith SL](https://www.ncbi.nlm.nih.gov/pubmed/?term=Smith%20SL%5BAuthor%5D&cauthor=true&cauthor_uid=28425318), [DeGrace B](https://www.ncbi.nlm.nih.gov/pubmed/?term=DeGrace%20B%5BAuthor%5D&cauthor=true&cauthor_uid=28425318), [Ciro C](https://www.ncbi.nlm.nih.gov/pubmed/?term=Ciro%20C%5BAuthor%5D&cauthor=true&cauthor_uid=28425318)1, [Bax A](https://www.ncbi.nlm.nih.gov/pubmed/?term=Bax%20A%5BAuthor%5D&cauthor=true&cauthor_uid=28425318), [Hambrick A](https://www.ncbi.nlm.nih.gov/pubmed/?term=Hambrick%20A%5BAuthor%5D&cauthor=true&cauthor_uid=28425318), [James J](https://www.ncbi.nlm.nih.gov/pubmed/?term=James%20J%5BAuthor%5D&cauthor=true&cauthor_uid=28425318), [Evans A](https://www.ncbi.nlm.nih.gov/pubmed/?term=Evans%20A%5BAuthor%5D&cauthor=true&cauthor_uid=28425318). Exploring families' experiences of health: contributions to a model of family health. Psychol, Health Med 2017; 20: 1-9

31 [Nordin C](https://www.ncbi.nlm.nih.gov/pubmed/?term=Nordin%20C%5BAuthor%5D&cauthor=true&cauthor_uid=28100440), [Michaelson P](https://www.ncbi.nlm.nih.gov/pubmed/?term=Michaelson%20P%5BAuthor%5D&cauthor=true&cauthor_uid=28100440), [Eriksson MK](https://www.ncbi.nlm.nih.gov/pubmed/?term=Eriksson%20MK%5BAuthor%5D&cauthor=true&cauthor_uid=28100440), [Gard G](https://www.ncbi.nlm.nih.gov/pubmed/?term=Gard%20G%5BAuthor%5D&cauthor=true&cauthor_uid=28100440).  It's About Me: Patients' Experiences of Patient Participation in the Web Behavior Change Program for Activity in Combination With Multimodal Pain Rehabilitation. J Med Internet Res 2017; 18: (1):

32 [Wiklund Axelsson S](https://www.ncbi.nlm.nih.gov/pubmed/?term=Wiklund%20Axelsson%20S%5BAuthor%5D&cauthor=true&cauthor_uid=27999272), [Wikberg-Nilsson Å](https://www.ncbi.nlm.nih.gov/pubmed/?term=Wikberg-Nilsson%20%C3%85%5BAuthor%5D&cauthor=true&cauthor_uid=27999272), [Melander Wikman A](https://www.ncbi.nlm.nih.gov/pubmed/?term=Melander%20Wikman%20A%5BAuthor%5D&cauthor=true&cauthor_uid=27999272). Sustainable Lifestyle Change-Participatory Design of Support Together with Persons with Obesity in the Third Age. Int J Eviro Res Public Health 2016; 16: E1248

33 Thorén-Jönsson, A. and Grimby, G Ability and perceived difficulty in daily activities in people with poliomyelitis sequelae 2001; J Rehabil Med:33 4-11.

34. World Health Organisation Guidelines on Health-Related Rehabilitation. 2016; Available at [http://who.int/disabilities/care/rehabilitation\_guidelines\_concept.pdf. Accessed on the 17/05/2017](http://who.int/disabilities/care/rehabilitation_guidelines_concept.pdf.%20Accessed%20on%20the%2017/05/2017)

35. Nam KY, Lee S, Yang EJ, Kim K, Jung SH, Jang SN, Han SJ, Kim WH, Lim JY Falls in Korean Polio Survivors: Incidence, Consequences, and Risk Factors 2016 [J Korean Med Sci.](https://www.ncbi.nlm.nih.gov/pubmed/26839487) 2016 31:301-9

36 Scobbie L, Duncan E, Brady M, Wyke S Goal setting practice in services delivering community-based stroke rehabilitation: a United Kingdom (UK) wide survey.  Disabil Rehabil 2015; 37:1291-1298.

36. [Atreja A](https://www.ncbi.nlm.nih.gov/pubmed/?term=Atreja%20A%5BAuthor%5D&cauthor=true&cauthor_uid=16369309), [Bellam N](https://www.ncbi.nlm.nih.gov/pubmed/?term=Bellam%20N%5BAuthor%5D&cauthor=true&cauthor_uid=16369309), [Levy SR](https://www.ncbi.nlm.nih.gov/pubmed/?term=Levy%20SR%5BAuthor%5D&cauthor=true&cauthor_uid=16369309) Strategies to enhance patient adherence: making it simple. 2005; 7: 4

37 Atwal A, Giles A, Spiliotopoulou G, Plastow N, Wilson L Living with polio and postpolio syndrome in the United Kingdom. Scand J Caring Sci 2013; 27: 238-45.

38 Whitaker K, Ghanouni A, Zhou Y, et al. Patients’ preferences for GP consultation for perceived cancer risk in primary care: a discrete choice experiment. Br J Gen Pract  2017; May 8th

39 [Santos-Tavares I](https://www.ncbi.nlm.nih.gov/pubmed/?term=Santos-Tavares%20I%5BAuthor%5D&cauthor=true&cauthor_uid=22353041), [Thorén-Jönsson AL](https://www.ncbi.nlm.nih.gov/pubmed/?term=Thor%C3%A9n-J%C3%B6nsson%20AL%5BAuthor%5D&cauthor=true&cauthor_uid=22353041) Confidence in the future and hopelessness: experiences in daily occupations of immigrants with late effects of polio. Scad J Occup Ther 2013; 20: 9-20

40. Boyle D, Coote A, Sherwood C, Slay J . Right Here Right Now 2010. NESTA. Available at <http://www.nesta.org.uk/sites/default/files/right_here_right_now.pdf>. Accessed 30/08/2017

41 [Lexell EM](https://www.ncbi.nlm.nih.gov/pubmed/?term=Lexell%20EM%5BAuthor%5D&cauthor=true&cauthor_uid=25893398), [Lexell J](https://www.ncbi.nlm.nih.gov/pubmed/?term=Lexell%20J%5BAuthor%5D&cauthor=true&cauthor_uid=25893398), [Larsson-Lund M](https://www.ncbi.nlm.nih.gov/pubmed/?term=Larsson-Lund%20M%5BAuthor%5D&cauthor=true&cauthor_uid=25893398). The rehabilitation plan can support clients' active engagement and facilitate the process of change - experiences from people with late effects of polio participating in a rehabilitation programme. [Disabil Rehabil.](https://www.ncbi.nlm.nih.gov/pubmed/25893398) 2016;  38: 329-36

42. Bryman, A. (2015) Social research methods. Oxford university press

43 Fusch PI. and Ness LR. Are we there yet? Data saturation in qualitative research', The Qualitative Report 2015; 20: 1408-1416

Table 1 : Outline of semi structured interview questions

|  |
| --- |
|  |
| 1. How did you first find out about the programme? |
| 2. When you were first invited to the programme how did you feel? |
| 3. How was your experience of being on the programme? |
| 4. What words would you use to describe the programme and how did it make you feel? |
| 5. What advice and strategies were given to you in the programme? |
| 6. Have the experiences/strategies from the programme influenced your life since? |
| 7. What would you have found useful in the programme? |

Table 2: Demographics of Participants

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Participant |  |  | Daniel | Jill | Andrea | Susan | Tom | Paul | Maria | Mark | Jessica | Beth |
| Demographics | Mean age | 70 | 64 | 83 | 75 | 62 | 72 | 68 | 59 | 77 | 66 | 70 |
| Age range | 59-77 |  |  |  |  |  |  |  |  |  |  |
| Gender | 6 Female  4 Male |  | F | F | F | M | M | F | M | F | F |
| Ethnicity |  | British | British | British | British | British | White British | White European | White British | British | British |
| Other treatments for PPS used by participants. |  | Electrical tests | No | Physio/  Acupuncture (private) | Chiropractor, Massage | Orthotic shoes | General rehab swimming | Physio, Osteopathy, Hydrotherapy | Physio at Hydrotherapy Rehab gym | Painkillers | Hydrotherapy, Neurophysio (NHS- not regular), yoga |
| Medical history | year polio contracted | 1940- 1961 | 1957- aged 5 | 1957 | 1942- age around 1 | 1953- Italy- aged 13 days | 1952-53 | 1956- aged 9 | 1961- aged around 4 | 1940- aged 2 | 1953- aged around 3 | 1955- aged around 9 |
| Impairment from polio  LL= Lower leg  UL=Upper Limb |  | LL | LL-bilateral | LL- severe weakness left limb | UL complete paralysis at onset.  Right arm fully paralysed.  Left shoulder and chest weakness | LL- weakness in left leg | LL+ spine. | LL- right leg. Some lower leg and foot muscles | LL- acute weakness | LL & spine: general weakness on left leg and spine | LL- paralyzed waist down. Some mobility regained. Not able to run, stand from floor |
| Age  PPS developed range between 36-73 | 52.5 | 48 | 55 | 50 | 36 | 57 | 55 | 55 | 73 | 45 | 51 |
| Age medical advice sought range 38-74 | 53.8 | 48 | 55 | 58 | 38 | 58 | 55 | 56 | 74 | 45 | 51 |
| Reported weakness/limitations of PPS on development of symptoms (no reporting symptom) |  | Flu like symptoms & pain in back | couldn't run, play tennis and or  walk dogs | Reduced mobility | Lifting left arm  Achy legs, Fatigue | Falls.  Muscle loss in right leg | Falls,  Fatigue,  Decreased balance, Pain in shoulder | Fatigue, falls  (fractured right femur in good' leg) | Following fractured femur in 2012 significant loss of strength in left leg | Mobility Pain | Pain, fatigue in legs.  Lack of confidence and balance |

Table 3: Overview of the programme and year attended by each participant

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Participant and Year Attended** | Daniel  2006 | Tom  2001 | Andrea  2011 | Susan  2001 | Jill  2008 | Paul  2013 | Maria  2014 | Mark  2014 | Jessica  Late 1990s | | Beth  2015 |
| **Program type** | Group residential | | | | | | | | Exercise  Goal Setting  Meaningful activities  Coping Strategies | | Exercise, Pacing |
| **Professional involvement** | Occupational Therapists, Physiotherapist, Medical Doctors, Dietician and Psychologists. | | | | | | | | | Psychology  Occupational Therapy  Physiotherapy | Physiotherapist |
| **Duration** | 9 days (over 3 weeks), 1 day review 6 months later | | | | | | 6 days (over 2 weeks), 1 day review 6 months later | | 5 days (over 2 weeks) | | 1 day weekly session. Indefinite. |

Table 4: Content of Group Residential Programme over 9 days.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **DAY 1** | **DAY 2** | **DAY 3** | **DAY 4** | **DAY 5** | **DAY 6** |
| Introduction to the course | Relaxation theory and practice | Pain mechanism and pain control | Energy conservation | Fatigue management | Exercise progression |
| Polio knowledge test | Life style planning | Ergonomics | Joints and posture | Sleep | Course evaluation |
| Paper based assessments | Coping styles | Assistive devices | Thinking patterns workshop | Communication | Goal setting |
| OT/PT assessments | Falls therapy | Nutrition and PPS | Hydrotherapy | British Polio Fellowship |  |
| Introduction to PPS | Goal setting theory | Assessments |  | Q&A with consultant |  |
| Introduction to exercise | Thinking styles |  |  |  |  |