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Published in:
Journal of Rehabilitation Medicine

DOI:
[10.2340/16501977-0559](https://doi.org/10.2340/16501977-0559)

2010

[Link to publication](#)

Citation for published version (APA):
Larsson Lund, M., & Lexell, J. (2010). A positive turning point in life--how persons with late effects of polio experience the influence of an interdisciplinary rehabilitation programme. *Journal of Rehabilitation Medicine*, 42(6), 559-565. <https://doi.org/10.2340/16501977-0559>

Total number of authors:
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Citation for the published paper:
Maria Larsson Lund, Jan Lexell

"A positive turning point in life--how persons with late effects of polio experience the influence of an interdisciplinary rehabilitation programme."

Journal of Rehabilitation Medicine 2010 42, 559 - 565

<http://dx.doi.org/10.2340/16501977-0559>

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Rehabilitation Information

A positive turning point in life

**How persons with late effects of polio experiences the influence of
a interdisciplinary rehabilitation programme**

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Short title: Experiences of rehabilitation in persons with late effects of polio

ABSTRACT

Objective: To describe and enhance our understanding of how persons with late effects of polio experience the influence of a comprehensive interdisciplinary rehabilitation programme.

Participants: Twelve persons with clinically verified late effects of polio who had taken part in an individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme.

Method: Qualitative research interviews analysed with the constant comparative method of Grounded theory.

Results: The rehabilitation programme was experienced as a turning-point in the participant's life. Before rehabilitation they felt being in a downward slope without control. Rehabilitation was the start of a process of change whereby they acquired new skills which, over time, contributed to a different but good life. After about a year, they had a sense of control and had accepted life with late effects of polio. They had also established new habits, taken on a changed valued self and could look at their future with confidence.

Conclusion: This qualitative study has shown that persons with late effects of polio can benefit from a comprehensive interdisciplinary rehabilitation programme and experience positive changes in their management of daily activities and in their view of their late effects of polio, their future and their self.

Key words

Activities of daily living; Disease management; Patient education; Postpoliomyelitis syndrome; Rehabilitation; Treatment outcome

INTRODUCTION

Late effects of polio, also referred to as post-polio syndrome, affects a large proportion of those who have acquired paralytic poliomyelitis (1). It is characterised by new symptoms, mainly progressive muscle weakness, muscle atrophy, pain and fatigue (1-3). This often leads to limitations in the performance of housework, leisure activities and work (4-6). Perceived participation in a variety of situations can also be affected (7), and health related quality of life (8) as well as life satisfaction (4, 9, 10) is reported to be lower compared with a normal population. Illness narratives of persons with late effects of polio confirm that their daily life becomes increasingly difficult (11). Studies of their adaptation (12-14) have shown that it is a complex process involving life-style changes and the need to use a variety of adaptive strategies to manage their problems, to come to terms with changes in their capability and to modify their self (12-14).

There is an international agreement that persons with late effects of polio can benefit from being admitted to a team specialised in late effects of polio (1, 2, 15, 16). In the EFNS Guidelines on the diagnosis and management of post-polio syndrome (17) it is stated that group training, regular follow-up and patient education are useful for the patients' mental status and well-being and give a more positive experience of self. This indicates that persons with late effects of polio, with the support of rehabilitation professionals, go through a process of change leading to a better life. However, no study has investigated how rehabilitation contributes to such a process of change. One uncontrolled pilot study (18) examined the effects of a comprehensive programme combining physical exercise with education. There were significant improvements in endurance, depression and fatigue, but no significant changes in muscle strength and anxiety. Both the patients and the professionals reported other benefits of the programme, but these were not quantified. McNaughton et al. (2) has pointed out that aspects of rehabilitation that are important for persons with late effects of polio are missed because of the lack of appropriate outcome tools. To understand the benefits of rehabilitation programmes for persons with chronic conditions, such as late effects of polio, Cooper et al. (19) have argued for the use of both qualitative and quantitative methods. With qualitative methods, the outcome of a rehabilitation programme and the process by which the outcome has emerged can be explored from a patient perspective.

The aim of this qualitative study was to describe and enhance our understanding of how persons with late effects of polio experience the influence of an individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme.

METHODS

Participants

A purposive sampling (20) of participants with late effects of polio was made from the database in a rehabilitation clinic in a university hospital in the south of Sweden. All potential participants had taken part in an 8-week individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme. At the time of the study, the database included 158 persons with late effects of polio; 44 individuals had taken part in the 8-week programme and the subsequent one-year follow-up, whereas the remaining individuals had received other targeted interventions that were completed over a period of 6-18 weeks.

All potential participants were community-dwelling and had a confirmed history of acute poliomyelitis with new symptoms after a period of functional stability. An electromyogram (EMG) had been recorded in the upper and lower limbs as part of the initial clinical examination and verification of prior polio. The specific inclusion criteria were: a) the participants should not before have taken part in an individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme; b) at least nine months and a maximum of 18 months should have elapsed from discharge from the programme. As the intention was to form a base for the study that was as rich and accurate as possible (20), a width of experiences were sought by selecting participants that were of both sexes, married or living alone, working or not working (retired or permanent disability pension) as well as of different ages, ethnicity and functional level. At first, 12 persons (four women and eight men) were asked to participate. When the last interviews were analysed, they added no new information to the categories that had evolved, and no additional persons were asked to participate. Five participants were interviewed 18 months after discharge from the rehabilitation programme, five after 12 months and two after 9 months.

The ages of the 12 participants varied from 40 to 73 years (mean 60 years). Their mean age at the acute poliomyelitis infection was 7 years and they had acquired polio between 1936 and 1966. The duration of new symptoms representing late effects of polio was 7 years. Eight participants were married or cohabited and four lived alone. Five persons worked part time, four had permanent disability pension and three had retired. One participant was of Arabic origin and the others Scandinavian. All participants reported varying degrees of symptoms (impairments) representing late effects of polio, such as muscle fatigue, muscle weakness, general fatigue, muscle and/or joint pain during physical activity and cold intolerance. They were all ambulant (four persons used a mobility aid, a stick), but reported different activity limitations and participation restrictions.

The rehabilitation programme

All individuals with a history of polio that were referred to the clinic were assessed by the rehabilitation team. The team consisted of a rehabilitation medicine physician, a physiotherapist, an occupational therapist, a social worker and a psychologist; all team members had experience of both interdisciplinary teamwork and rehabilitation of persons with late effects of polio. Based on the initial assessment and the nature and extent of their disability, individuals could be recommended to take part in the 8-week individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme. The focus of the rehabilitation program was to reduce self-perceived disability by providing a variety of interventions and thereby maximize each individual's physical, mental and social potential. Individuals who were not recommended the 8-week programme were instead offered other individualised targeted interventions that were completed over a period of 6-18 weeks.

The 8-week rehabilitation programme started with a two-week period, 4 hours a day, at the rehabilitation clinic, together with 5 to 7 other participants. During the first week, they participated in lectures about late effects of polio, about rehabilitation, and about various interventions and self-management strategies. One central component of the educational programme was the rehabilitation plan, its content and how the participants should use it during and after the rehabilitation period. The rehabilitation plan was based on the International Classification of Functioning Disability and Health (ICF) (21) and comprised three parts: the assessments (focusing on the consequences of late effects of polio), the goals and interventions, and the continuation following the rehabilitation period. During the first and second week, each participant was assessed in-depth by each team member and was also able to try different aids, compensatory techniques and other medical and non-medical interventions. Family members were also invited to take part during the two-week period. Based on this extensive assessment and their own needs, each participant defined together with the team members his/her rehabilitation goals, focusing primarily on activity and participation. The goals were written on the rehabilitation plan, which each participant could refer to during the remaining rehabilitation period and at follow-ups. During the coming six-week period, the participants followed the rehabilitation plan at home and/or at work and returned for a formal discharge eight weeks after the start of the programme, when the different goals were evaluated. At the discharge conference, a plan for the next four months was written. Each participant was then followed-up four months after discharge and after a further six months (i.e., twelve months after the start of the programme). All participants were thereafter offered to take part in the clinic's life-long follow-up program.

Data collection

Qualitative research interviews (22) were conducted at the rehabilitation clinic by the first author (MLL), who had not been involved in the rehabilitation programme. An interview guide was used, containing a few broad questions that covered the participants' experiences of living with late effects of polio from the time before the rehabilitation programme, their expectations of the future and their experiences of the influence of the rehabilitation programme. The participants were interviewed once and the interviews lasted between 60 and 100 minutes (mean 75 minutes). All interviews were tape-recorded and transcribed verbatim.

Data analysis

The interview transcriptions were analysed using the constant comparative method of Grounded theory (23). This method was chosen based on the aim of the study. It enables the researcher to inductively uncover patterns of actions and processes present in peoples' experiences. First, the transcriptions were read in order to obtain a sense of the overall data and of the participants' experiences of the rehabilitation programme. The analysis continued by breaking down the experiences into parts and by giving them a code. Thereafter, the codes in each interview were compared against each other and the codes that seemed to pertain to the same phenomenon were grouped to a preliminary sub-category. The preliminary sub-categories that were obtained from each interview were then compared to establish sub-categories. In the next step, the sub-categories were organised in relation to each other and into four categories. In this phase, it became evident that the sub-categories could be related to each other with regard to the different periods of time when they were present in the participants' descriptions. Finally, the core category that captured the essence of the participants' experiences of the rehabilitation programme was identified. The codes, sub-categories, categories and the core category were formulated as close as possible to the participants' own words to remain as true as possible to the data. To ensure that the findings were grounded in the data and the completeness of them, the emerging codes and categories were compared during the analysis with all the data. The first author, who was responsible for the analysis, discussed the results with the second author when all the results had emerged. The second author had access to all raw data and his comments were accommodated in the final step of the analysis to refine the results and to ensure the validity of the data.

RESULTS

The experiences of the participants formed the core category "The rehabilitation programme was a positive turning-point in life", which is illustrated with the following quote:

"For me, it [the rehabilitation programme] was in some way the beginning of the rest of my life, it was a real turning point [15]".

The core category comprised four categories that reflected their experiences of a process of change, from before rehabilitation up to the interview: "Being in a downward slope without control"; "Being supported in a process of change in a positive direction"; "Struggling with the process of change to master daily life"; and "Passing through the process of change to a different but good life". These categories each comprised three to five sub-categories (Figure 1). Based on the participants' experiences, the categories appeared in chronological order. Although no fixed starting and finishing points existed, certain experiences took precedence over time and thereby formed the categories. The participants' descriptions in the four categories showed that it was an ongoing and iterative process. As they described their own processes, the categories and the sub-categories within each category were intertwined in a unique way for each participant.

Being in a downward slope without control

This category comprised three sub-categories that depict the participants' experiences before rehabilitation of being in a downward slope without control and not being able to do anything about it. During this time, the participants' experiences often hovered between two extremes, the very pessimistic and the optimistic.

Not being the one I used to be. The participants experienced increasing difficulties performing daily activities and a need to rest during daytime. They became aware of their progressive muscle weakness, their pain and fatigue. At first, the participants hoped that their symptoms would disappear, but over time they became more and more concerned, which caused feelings of distress, frustration and irritation. They also perceived that they had changed in a negative way and that they were not the person they used to or wanted to be.

Being unsure about the future. The participants' experiences reflected their struggle to manage daily life and they said that they had asked themselves how long they could actually manage. They felt powerless as they did not understand what caused their symptoms and what they, or health care professionals, could do to help them. Some participants exaggerated the

negative consequences, while others tried to take one day at a time. They were also unsure about their future, which is illustrated with the following quote:

“I thought, if it goes on like this and continues to go downhill, then I have no life any longer [I 6]”.

Being afflicted with polio a second time. The participants described how they searched for explanations of their symptoms and that they, often by coincidence, were told that they had late effects of polio. They could not believe it, as it was experienced as having polio a second time.

Being supported in a process of change in a positive direction

This category and the four sub-categories pertained to the participants' experiences of how the rehabilitation programme supported their process of change in a positive direction. The participants often reflected over their new knowledge and experiences and how to integrate them in their life.

Learning about late effects of polio and how to manage the difficulties. When the participants learned about late effects of polio they recognized their own symptoms and difficulties, which they felt confirmed that they really did have it. According to the participants, learning about the long-term consequences made them realise that they had to alter their way of thinking and adapt their daily life to prevent deterioration. One participant said:

“The curves had the strongest impression on me [a graph used during the programme to illustrate the effects of normal aging on muscle function and the additional effect of late effects of polio] and my first reaction was, I had to straighten them out [I 3]”.

During the programme, the participants learned to conserve energy by planning and adapting their performance of daily activities, by altering their physical environment and by exercising in a new way. The participants experienced that they were overwhelmed with the new information, but were gradually convinced that these strategies were worth trying to get a better life.

Reflecting on the self. The participants said that their increased knowledge made them reflect upon their perceptions of themselves in the past, at present and in the future, and they started to see themselves in a new perspective. They expressed that they now were afraid of who they

would become. They also thought of how close persons would react to the changes they needed to do and if this would negatively impact on these persons' perceptions of them.

Encountering others with late effects of polio provide awareness and hope. According to the participants, sharing experiences and difficulties with the other participants during the programme helped them to understand their own situation. Meeting others with similar symptoms also developed their awareness of what was important and beneficial for them. The participants' descriptions showed that they assessed their condition in relation to the other participants. A common experience was that there were always others who were worse off, which was difficult to face in relation to the future. At the same time, those who were worse off still lived a good life, which provided hope.

Writing a rehabilitation plan contribute to increased awareness. The participants described how they were taught to write their own rehabilitation plan, which at first were experienced as strange and difficult. This forced them to reflect over their life and their difficulties to manage daily activities as well as what they wanted to be able to do and achieve in the future. The participants told that this made their situation much clearer and it assisted them to describe their difficulties and needs to the rehabilitation team. As the rehabilitation plan focused on their daily life, they perceived that the rehabilitation programme was directed towards them as individuals rather than their late effects of polio per se. The fact that they wrote the rehabilitation plan themselves increased their awareness of the necessary changes in their daily life and their own responsibility to accomplish these changes. One participant said:

"When I wrote the rehabilitation plan, it forced me to write down and really think about what do I need, so it was very good; also, it is I that express these things and I that have to think about my life and take responsibility for it [I 12]".

Struggling with the process of change to master daily life

This category comprised four sub-categories, reflecting that the participants' struggle with different changes was an ongoing and iterative process. Based on their new knowledge, they strived to master their daily life in a new way.

Taking responsibility for the rehabilitation plan. The participants felt that they had to be responsible for their own rehabilitation plan and carry out the changes that were needed. This was experienced as quite demanding, as illustrated with the following quote:

“I realize that it is all about me, that I have to do these things myself [I 7]”.

The participants told that the rehabilitation plan supported their process of change by repeatedly reminding them to reflect on how they performed their daily activities and what they had to change. The plan also helped them to reflect on their achievements and which activities and changes they had to work on.

Struggling to establish new habits. The participants’ insight that their condition required irrevocable changes in their life and daily activities provoked an inner discomfort that they struggled with. This is illustrated with the following quote:

“It was very difficult when I came home [after the rehabilitation programme], I cried a lot as I realised I had to change my life drastically, I shall not be as active as before [I 10]”.

They told that they repeatedly struggled to adopt new ways to plan their time use, which implied that they did fewer activities and that others took over some of their activities. To establish new habits, they had to do their activities in new ways, applying energy conserving techniques, changing the pace and altering the placement of objects. In the beginning, they said that they felt uncomfortable as it often required their full attention and most activities were more difficult to perform. The participants told that their reflection on their new habits made them understand more clearly how the late effects of polio caused their fatigue. Gradually, they discovered that the adaptations that they learned during the rehabilitation programme lead to substantial improvements in their daily life. This came as a surprise but also provided them with strength to continue striving to establish new habits.

Even though the participants felt that they gradually succeeded to adapt, they described that they often reverted to their previous deep-rooted habits. The adaptation of their activities was therefore an ongoing and iterative process and it took time to establish new habits. One participant said:

“You know, you are aware of what mistakes you do, but you can not change everything during one or two weeks, but you can change bit by bit [I 6]”.

They described that their new habits also meant that they had to involve others, both at home and at work, in another way than before. They were also worried about reactions from others when they informed them and they too realised that they had to change their habits to support them to adapt to a new life with late effects of polio. However, they described that they mostly had positive responses and received respect and support in their struggle to change.

Struggling to redefine the self. An important part of the process of change at this phase was the participants' ongoing struggle to redefine their self, which is illustrated with this quote:

"You have regrets at the loss and you need to reorientate and find a new way to relate to one's self, to your self-image [I 12]".

The participants did not perceive themselves as the same person as before they experienced their late effects of polio symptoms or before the rehabilitation programme, but they did not see themselves as handicapped now. The struggle to redefine their self was described as the most difficult part and much more difficult than adapting their activities. One participant said:

"The most difficult is, anyhow, to realize that you are disabled [I 11]".

Passing through the process of change to a different but good life

This category and the five sub-categories were formed by the participants' experiences of passing through the process of change towards a different but good life. The participants had made the changes needed in their life and, therefore, they experienced that they had passed through the process of change, even if they had to continue to manage problems and needs.

Having a sense of control how to manage late effects of polio. The participants described that their theoretical knowledge and practical experience had helped them to develop a greater sense of control of their late effects of polio. Even if new difficulties aroused they said that it was easier to handle them, which had a positive effect on how they managed their daily life.

This is illustrated with the following quote:

"My life was awkward before [the rehabilitation programme], and now it is just more manageable, with things that makes one able to weave one's life... in a better way [I 12]".

The knowledge had also provided them with the strategies to change their daily activities which, in turn, helped them to reduce stress and overuse of muscles as well to conserve energy.

Having established new habits. The participants said that they had established new habits and acted, more or less deliberately, in accordance with what they had learned. According to the participants, the adaptation of their activities had given them a better balance between their different activities and their need for rest. This influenced their life in a positive way, which is illustrated with the following quote:

“Everything was tough [before the rehabilitation program], but in many way it is easier now, much in the way I plan my life [I 5]”.

Some of the participants described that their previous deep-rooted habits still influenced them, and chose to apply only those parts of the rehabilitation programme that they found useful. They explained that they were not interested or did not need to do any additional changes.

Accepting a life with late effects of polio. Some of the participants said that they had accepted their late effects of polio and that they had learnt to live with it, which is illustrated with the following quote:

“I feel really good as I have learnt to live with my disability [I 9]”.

Others said that they were about to accept their late effects. They avoided seeing their symptoms and the expected deterioration as an obstacle. Instead, they thought about all the possibilities in life when they had managed their difficulties. They described a good life, even though it was different in many ways. Depending on how much they were affected, some participants said that the rehabilitation programme had had a positive effect on their overall life, whereas others said that life continued to be good, regardless of the programme.

Taking on a changed valued self. The participants’ experiences reflected that they now understood and accepted their late effects of polio in relation to their self. They had changed their view of themselves and were about to take on, or had taken on, a new changed self that they valued more than before the rehabilitation programme. One participant said:

“It feels good to have accepted it, I am disabled but life is pretty good anyway [I 11]”.

Looking at the future with confidence. As the participants now perceived that they had much better strategies to manage their late effects of polio, it gave them the confidence that their future life would be much less affected than they had previously feared. Thereby, their worries and anxiety for the future had decreased and they could plan their life differently than before, despite their progressive physical disability. This is illustrated with the following quote:

“I can plan for the future in another way [than before the rehabilitation programme] and, above all, look at the future with confidence [I 8]”.

DISCUSSION

This study has shown that persons with late effects of polio, who adopt self-management strategies during an individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme, can experience a positive turning point in life. During a process of change, that formed the turning point, they acquired new skills which contributed to a different but good life. This confirms the previous uncontrolled quantitative study (18), that persons with late effects of polio can benefit from a comprehensive rehabilitation programme. In comparison with that study (18), which only demonstrated improvements in endurance, depression and fatigue, the present study has shown that the persons with late effects of polio can experience considerable positive changes in their management of daily activities and in their view of their late effects of polio, their future and their self. This is in agreement with previous qualitative research of other groups of people with chronic diseases (24, 25) and shows that that rehabilitation can initiate a process of change as well as result in improved abilities to manage a disease or disability. The persons experienced that the benefits of the program developed by an ongoing and iterative process that took at least a year to go through, which implies that outcome of a comprehensive interdisciplinary goal-oriented rehabilitation programmes has to be assessed in a long term perspective.

The results cannot be used as a predictable trajectory of the rehabilitation process, fixed in different stages, as the experiences were intertwined in unique ways for each participant. However, the linear order of the participants' experiences of the process differ from a non-linear process, that can also can take place (26). Thus, both linear and non-linear processes can occur when people try to manage the consequences of a chronic disability

The participants' overall experiences of the rehabilitation programme were characterized as a turning point. According to Mandelbaum (27), turning points are principal periods in life marked by transitions that signify development of a person's life history, and include alterations in a person's roles, relations and self-conceptions. The participants described a process of change where they took responsibility for various alterations to overcome problems in their lives. Their acting can be characterized as an empowerment process (28, 29) evolving as a result of the rehabilitation programme, in which the participants took an active role in their own rehabilitation process.

The participants' view of their self was crucial during the entire process and changes in their self were described as the most difficult to manage. This is in agreement with research on the rehabilitation process of people with physical disabilities (30). A meta-synthesis (31) has found that a key component to achieve health related behavioural changes

is reappraisal of self. The dual processes of identity shifts and behavioural changes interact and depend on each other. So, if a behavioural change strengthens a new identity, more behavioural change will follow. Previous studies of persons with late effects of polio (14) and other chronic illnesses (32-34) also show that reappraisal of self is a difficult and often complex process. The participants in the present study also described, in agreement with previous research of experiences of rehabilitation (30), that they had to manage the reappraisal of self mainly by themselves, which implies that rehabilitation programmes need to support people with late effects of polio to help them to manage changes in their self.

Changes in daily activities and habits were also crucial during the different phases of the process of change. Kielhofner (35) suggests that identity and competence in activities develop together during a continuous adaptive process, through engagement in activities. Thus, the inclusion of activities as goals in a rehabilitation programme can facilitate a process of change. However, previous deep-rooted habits prevented some participants from fully achieving all their activity goals. A synthesis of habit theories (36) indicate that habits are a powerful force that determines the course of peoples life in both a health promoting and a destructive direction. Therefore, Clark and colleagues (36) suggest that rehabilitation professionals must recognize how habits operate in peoples' lives and also emphasize the utility of habits in rehabilitation programmes.

Writing one's own rehabilitation plan was important in the process of change. The use of a person-driven plan has been emphasized in the rehabilitation of persons with late effects of polio (2). The participants in the present study described that the plan was a tool that had different meanings and purposes during their process of change. This is in contrast to previous research (37-39) that has focused on the usefulness of a plan as an outcome measure at the end of a rehabilitation period. The participants' experiences indicate that the plan can, and perhaps should, instead be used as a tool to empower them and to increase their awareness of their own situation, their needs, goals and possibilities as well as their own responsibility to adopt different management strategies.

Several studies (40-42) have highlighted the importance to enhance our knowledge of the "black box of rehabilitation". With that, professionals' ability to distinguish the "active ingredients" in the rehabilitation process is enhanced. One of the "active ingredients", based on the participants' experiences, was the rehabilitation plan and the way it was used during the programme. Setting goals in terms of activity and participation supported them in finding management strategies that enabled them to engage in desired tasks, despite their experience of a physical deterioration.

This qualitative study was not designed to generalize the results in a statistical sense. Instead, the intention was to gain an in-depth understanding of how persons with late effects of polio experience the influence of a rehabilitation programme. With regard to the concept of transferability (43), it is reasonable to believe that the experiences are not unique to the participants in the present study and that similar results will be obtained in studies of other persons undergoing rehabilitation. Despite the participants' struggle and negative experiences of the rehabilitation process, the result may be considered as an unrealistic and one-sided success story. However, the generalisation is limited to the twelve participants and it is impossible to know if other participants would have experienced the same. By selecting participants based on their quantitative outcome or those who drop-out from a program, future research can provide a more diverse picture of the experiences of this form of rehabilitation.

The purposive sampling strategy (20) that guided the selection process aimed to minimize bias and ensure the quality of data by maximising the range of experiences based on the participants' background. The fact that the interviews took place at the rehabilitation clinic and were related to effects of the interventions together with professionals that they still had contact with might have influenced their statements. As the interviewer was not involved in the rehabilitation programme and the participants' descriptions reflected an abundance of both positive and negative experiences, it is reasonable to believe that they genuinely shared their sincere experiences. Another possible limitation is the participants' memory of the rehabilitation programme and their retrospective interpretation of the events before, during and after the programme (22, 43). Apparently, the rehabilitation programme was a significant event in the participants' lives and they rarely hesitated when they described their experiences, so the interview data were rich and deep, despite its retrospective character. The possibility that the authors pre-understanding and interpretation influenced the results in a certain direction should also be considered. Several deliberate choices were made to reduce this possibility. The first author, who carried out the entire analysis, had no experience of late effects of polio, which is believed to enhance the openness to the data. The second author, who was involved in the rehabilitation programme, only took part in the final step of the analysis, to reduce the possibility of bias. Moreover, interpretations close to the participants' own experiences were sought throughout the analysis. Even if some categories may give the impression of being normatively laden this is not the case as the participants were full of expressions and used words as "accepting" and "turning point", which are all validated by the quotations.

The participants' experiences of an individual ongoing and iterative process indicate the importance of offering interventions that correspond to different individuals' need over time rather than providing a fixed programme. As the process of change proceeded over a year, rehabilitation programmes and rehabilitation plans should also have a long-term perspective. Most importantly, the results indicate that the effects of an interdisciplinary rehabilitation programme goes beyond that of simply reducing impairments. This, in turn, emphasizes the need to discuss and select appropriate outcome measures and to address the impact of rehabilitation programs in a broad sense. Ideally, a programme should affect the disability and future studies have to establish if the positive changes described here are accompanied by reduced impairments, and improved activity and participation.

In conclusion, this qualitative study showed that persons with late effects of polio can benefit from a comprehensive interdisciplinary rehabilitation programme. According to the participants, the programme was a positive turning point in their lives. Over time, they reported a sense of control of their lives with the establishment of new habits, an acceptance of a life with late effects of polio, a reappraisal of self and confidence in the future.

ACKNOWLEDGEMENTS

The authors are grateful to the persons who volunteered to participate. Maria Larsson Lund was supported by a personal grant from the Swedish council for working life and social research (FAS). Jan Lexell had received financial support from the Swedish Association of Survivors of Traffic Accidents and Polio (RTP), Stiftelsen för bistånd åt rörelsehindrade i Skåne and Skane county council's research and development foundation.

LEGEND

Figure 1. The core category with the four categories and their subcategories describing the experiences of persons with late effects of polio of the influence of an individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme.

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The rehabilitation programme was a positive turning-point in life

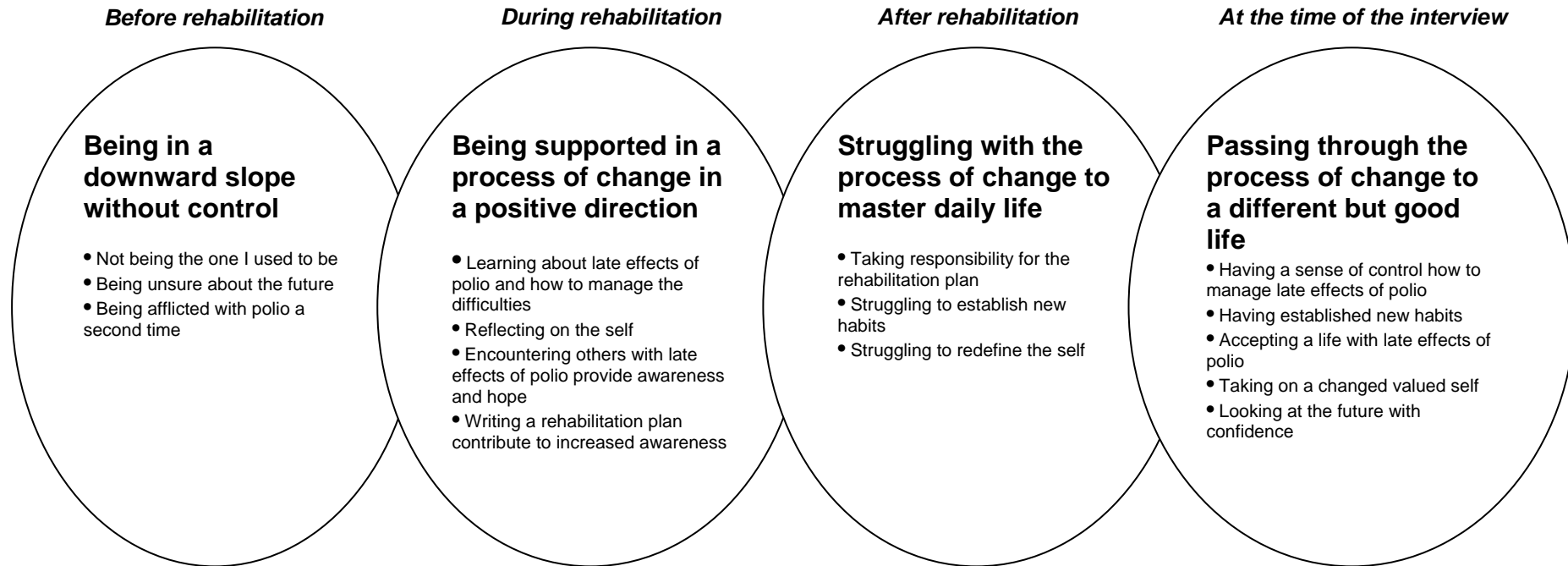


Figure 1