

ORIGINAL REPORT

PERCEIVED PARTICIPATION IN LIFE SITUATIONS IN PERSONS WITH LATE EFFECTS OF POLIO

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Objective: To investigate how persons with late effects of polio perceive their participation and problems with participation in life situations and to determine the association between perceived problems with participation and sex, age, marital status, use of mobility aids and access to instrumental support.

Design: Cross-sectional.

Subjects: A total of 160 persons with prior polio 6–30 months after an individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme.

Methods: All subjects answered the Swedish version of the Impact on Participation and Autonomy Questionnaire.

Results: A majority of the respondents perceived their participation as sufficient in most activities and 65% of the respondents perceived no severe problems with participation. The remaining 35% perceived 1–6 severe problems with participation. All 5 domains of participation were positively correlated with the 9 items for problem experience. Most restrictions in participation were reported in the domains of Family role, Autonomy outdoors, and Work and education. Insufficient instrumental support was most strongly associated with the perception of severe problems with participation.

Conclusion: Rehabilitation programmes for persons with late effects of polio need to focus on areas of participation that are perceived as a problem by these persons and to promote access to a supportive environment to enhance their participation.

Key words: activities of daily living, disability evaluation, disabled persons, personal autonomy, postpoliomyelitis syndrome, rehabilitation, social environment.

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INTRODUCTION

The adoption of the International Classification of Function, Disability and Health (ICF) (1) as a framework in the management of life-long disabilities has become an important issue in healthcare and rehabilitation (2–5). A new and central concept

in the ICF is “participation”, defined as involvement in life situations. The ICF emphasizes the need to understand the lived experience of people in the actual context they live, and accordingly disabled person’s own perceptions of their life situation. It is also known that insiders’ perceptions of participation can be different from their perceptions of “problems with participation” (6, 7). The development of instruments that assess both types of insiders’ perceptions is important in the application of the ICF framework in studies of persons with disabilities. One such instrument is the Impact on Participation and Autonomy (IPA) questionnaire (8–11), which has been used in a variety of disabling conditions and has increased our understanding of the relationship between a health condition, and environmental and personal factors.

So-called late effects of polio, also referred to as post-polio syndrome, is one of the most common neuromuscular conditions. It is estimated that up to 80%, or 5–15 million people around the world, will need healthcare and rehabilitation over the next 5 decades as a result of their acute poliomyelitis infection (12). Late effects of polio appear several decades after the acute infection, which is followed by a period of neurological and functional stability (12–14). It is characterized by new physical symptoms, mainly muscle weakness, muscle atrophy, pain and fatigue (12–15), and this often leads to limitations in the performance of self-care, mobility, home management, leisure and work (16–20). These impairments (12–15, 21, 22) and activity limitations (16–20) are such that people with late effects of polio may face a variety of challenges related to their participation, which may impact on their autonomy and, ultimately, their life satisfaction.

To design rehabilitation interventions for people with late effects of polio, we need detailed knowledge of their participation and restrictions herein, as well as factors restricting their participation. The identification of factors that are related to restrictions in participation can also enable clinicians to distinguish “persons at risk”. Since our knowledge of perceived participation in people with late effects of polio is very limited, factors influencing participation have not been determined.

The aim of this study was to investigate how persons with late effects of polio perceive their participation and problems with participation in life situations and to determine the association between perceived problems with participation and sex, age, marital status, use of mobility aids and access to instrumental support.

MATERIAL AND METHODS

Subjects

Potential respondents to this descriptive cross-sectional study were obtained from the database in a post-polio rehabilitation clinic in a university hospital in the south of Sweden. All potential respondents 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 routine clinical examination and verification of prior polio. All potential respondents had completed an individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme 6–30 months prior to the study. The focus of the rehabilitation programme was to reduce self-perceived disability by providing a variety of interventions and thereby maximize each individual's physical, mental and social potential. After discharge, all subjects had been offered to take part in the clinic's life-long follow-up programme. A total of 208 persons were contacted and 160 (77%) gave their written informed consent to participate in the study. Of the remaining 48 persons, 25 responded that they did not want to take part, whereas 23 persons did not respond at all.

Assessments

In the letter to the potential respondents the following was enclosed: information carefully explaining the study; an invitation to participate; an informed consent form; and the Swedish version of the IPA questionnaire (IPA-S) (9). A questionnaire was also enclosed to obtain information on the respondents' sex, age, marital status, vocational status, self-estimated walking ability and use of mobility aids. In addition, the respondents were asked if they received support from another person to be able to do what they wanted, referred to in the following as instrumental support, in areas of self-care, housework and leisure. There were 3 response options: (i) Yes and the support I receive is sufficient; (ii) Yes, but the support I receive is insufficient and I would have liked more/other support; and (iii) No and I do not need support.

The IPA-S addresses perceived participation in 31 items in the domains of autonomy indoors, family role, autonomy outdoors, social relations, work and education as well as perceived problems with participation in 8 items/areas. Two additional items that cover perceptions of helping and supporting other people and problems herein are, in accordance with the English version of the questionnaire (IPA-E) (11), included in the IPA-S. The items for perceived participation have 5 response options: very good; good; fair; poor; very poor. The 3 response options for perceived problems with participation are: no problems; minor problems; severe problems.

The IPA-S has been developed through a forward-backward translation of the Dutch original version of IPA (6, 8, 23, 24), and has been found to have good internal scale validity and reliability (10). An evaluation of IPA-E (11) has shown that the 2 new items load on the domain of social relationships and also confirmed the construct validity and test-retest reliability of the new items.

Statistics

Relative frequencies were calculated for all items of IPA-S. Reports of poor or very poor participation for all 32 items in the different areas were counted and summed for each respondent. The number of reports of perceived severe problems in the 9 items addressing problems with participation was also counted and summed for each respondent. To assess if the respondents' perceptions of participation were related to their perceptions of problems with participation, Spearman's rank-order correlation was used to determine the relationship between the domains of participation, based on the summed scores of reports of poor or very poor participation, and each of the 9 items for perceived problems with participation.

A logistic regression including both a univariate and a multivariate analysis was performed to determine the influence of sex, age, marital status, use of mobility aids and access to instrumental support (inde-

pendent variables) on the dependent variable, perceived problems with participation. In the analysis, age was best represented as a continuous variable whereas the other 4 independent variables were categorical. The dependent variable was dichotomized based on the summed scores of reports of severe problems with participation forming 2 groups, one for respondents who perceived no severe problems with their participation (no problems; minor problems) and one for respondents who perceived severe problems. The odds ratio (OR) shows the impact of an independent variable on the dependent variable in the presence of perceived problems with participation. An OR above 1.0 indicates an increased likelihood of perceiving severe problems with participation, and, conversely, an OR below 1.0 indicates a reduced likelihood. The OR is significant if the value 1 is not included in the 95% confidence interval (95% CI) of the OR, i.e. a significant association exists between the independent and dependent variables.

RESULTS

Of the 160 respondents, 48% were men and 52% women; of the 48 non-respondents, 35% were men and 65% women. The mean age of the respondents was 68 years (standard deviation (SD) 9.5, range 30–86 years) and of the non-respondents 70 years (SD 9.0, range 53–82 years). No significant differences were found between the respondents' and non-respondents' sex ($p=0.16$) and age ($p=0.22$). A majority of the respondents were retired (61%), were married or living with a partner (68%) and used some kind of mobility aids (walking aid 50%; wheelchair 23%). The respondents' walking ability varied from more than 1000 m (23%) to no walking ability at all (i.e. dependent on a wheelchair; 7%). Of the respondents, 46% received instrumental support and answered that it was sufficient, 8% received instrumental support but answered that it was not sufficient and that they needed more/other support, and 46% answered that they did not need any instrumental support.

Nearly all respondents (more than 96%) perceived their participation as sufficient (very good; good; fair) in items addressing mobility indoors and self-care (Autonomy indoors domain) (Table I). Perceptions of participation in items addressing communication, relationship and respect from other people as well as helping and supporting other people (Social relations domain) were also perceived as sufficient by more than 85% of the respondents. The largest proportions (38–48%) of insufficient (poor; very poor) participation were perceived in the items for heavy housework, repairs and upkeep of the home (Family role domain), going on trips and holidays (Autonomy outdoors domain), getting or keeping a job, getting a different job and, finally, getting training and education (Work and education domain). More restrictions in participation (poor; very poor) were reported in the domains of Family role, Autonomy outdoors, and Work and education than in Autonomy indoors and Social relations (Table II).

Table III shows that a large majority of the respondents perceived no or minor problems with various aspects of participation. A smaller proportion (4–22%) reported severe problems in the 9 items addressing problems with participation. The summed scores of reports of problem experiences with various aspects of participation showed that 65% of the respondents perceived no severe problems with their participation and that the remaining 35% perceived 1–6 severe problems.

Table I. Percentage of participation levels, as measured by the Impact of Participation and Autonomy, Swedish version (IPA-S) (9), in persons (n = 160) with late effects of polio

IPA-S items per participation domain	Very good (%)	Good (%)	Fair (%)	Poor (%)	Very poor (%)	n*
Autonomy indoors						
Getting around indoors where one wants	39	31	26	4	—	157
Getting around indoors when one wants	44	25	28	3	—	158
Washing, dressing, grooming the way one wants	40	41	18	1	—	160
Washing, dressing, grooming when one wants	47	34	18	1	—	160
Going to bed when one wants	50	34	14	2	—	160
Going to the toilet when one needs	53	36	10	1	—	160
Eating and drinking when one wants	58	38	4	0	—	160
Family role						
Contributing to looking after the home	24	36	31	8	—	159
Minor housework jobs the way one wants	37	40	20	3	—	158
Heavy housework jobs the way one wants	12	18	31	24	15	158
Getting housework done when one wants	21	22	39	14	4	159
Repairs and upkeep the home	7	14	31	28	20	149
Fulfilling one's role at home	17	35	36	12	—	155
Spending income as wished	34	33	22	10	1	159
Autonomy outdoors						
Visiting friends when one wants	30	20	38	8	4	158
Going on trips and holiday one wants	10	18	34	25	13	158
Spending leisure time the way one wants	25	31	30	13	1	157
Frequency of social contacts	24	35	30	9	2	159
Living life the way one wants	15	24	17	17	3	156
Social relations						
Communication on equal terms with close people	72	21	7	—	—	159
Relationship with close people	67	22	9	1	1	159
Respect from close people	69	24	7	—	—	160
Relationship with acquaintances	34	45	13	4	2	159
Respect from acquaintances	33	44	18	4	1	158
Intimate relationship	21	37	27	8	7	150
Helping and supporting people	27	36	25	10	2	158
Work and education						
Getting or keeping work one wants	20	23	17	23	17	140
Doing work the way one wants†	31	27	21	13	8	85
Contacts with colleagues†	52	29	11	3	5	75
Achieving or maintaining a position one wants†	40	24	19	8	9	75
Getting a different job†	17	22	16	20	25	69
Getting training or education one wants‡	27	19	19	23	12	69

*Number of respondents for each item.

†Respondents were instructed not to answer these items if they did not have paid or voluntary work.

‡Eighty-nine persons reported that this item was not relevant to them.

Table II. Reports of insufficient participation in different domains of participation in persons (n = 160) with late effects of polio

Items in each domain of IPA-S	Reports of insufficient participation (%)			
	0	1-2	3-4	≥5
Autonomy indoors (7 items)	94	5	1	—
Family role (7 items)	46	31	17	6
Autonomy outdoors (5 items)	55	31	12	2
Social relations (7 items)	78	18	4	—
Work and education (6 items)	51	40	6	1

IPA-S: Impact of Participation and Autonomy (Swedish version). Insufficient participation is represented by the summed scores of reports of poor or very poor participation. 0 = no reports of poor or very poor participation; 1-2 = 1 or 2 reports; 3-4 = 3 or 4 reports; ≥5 = 5 or more reports.

Table III. Percentage of problem experiences in various aspects of participation in persons (n = 160) with late effects of polio

IPA-S items on problem experience	No problems (%)	Minor problems (%)	Severe problems (%)	n*
Mobility	12	72	16	156
Self-care	40	56	4	160
Family role	28	65	7	155
Financial situation	48	44	8	159
Leisure	21	65	14	158
Social relations	43	51	6	159
Helping people	40	49	11	155
Work†	25	57	17	75
Education†	31	47	22	68

*Number of respondents for each item.

†Respondents were instructed not to answer these items if they were not relevant to them.

IPA-S: Impact of Participation and Autonomy (Swedish version).

All 5 domains of participation were positively correlated to the 9 items for problem experiences and a majority (87%) of the correlation coefficients were significant ($p < 0.05$; $r = 0.24-0.65$).

The logistic regression (Table IV) showed that access to instrumental support was the most important factor for perceived severe problems with participation. Reports of insufficient instrumental support were most strongly associated with perceived severe problems with participation. There was also a significant, but weaker, association between reports of sufficient instrumental support and perceived severe problems with participation. Being male was significantly associated with the presence of severe problems with participation, whereas the age of the respondents, their marital status and the need for mobility aids were not significantly associated with severe problems with participation.

DISCUSSION

The main results in this study were: (i) a majority of the individuals with late effects of polio perceived their participation to be sufficient in most of the items addressed and reported no or minor problems in various aspects of participation; (ii) persons who perceived sufficient participation reported few problems in participation; and (iii) insufficient instrumental support was most strongly associated with severe problems with participation.

To the best of our knowledge, no study has reported specifically and in detail perceived participation in various life situations in persons with late effects of polio. In a study by Cardol et al. (7), who developed the IPA Questionnaire, persons with neuromuscular disorders (including some individuals with late effects of polio) perceived a level of participation similar to that in the present study. They also reported fewer restrictions

than persons with other chronic disabilities, such as stroke and rheumatoid arthritis. Our results can also be compared with those of a group of 161 Swedish spinal cord injured persons who answered the IPA-S Questionnaire (9). A majority of these persons also perceived their participation as sufficient in most activities addressed. Taken together, these results imply that persons with late effects of polio, as well as other forms of physical disabilities, overall can perceive a fairly high level of participation. Both the persons in the present study and those with a spinal cord injury (9) had been part of an individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme. One might therefore infer that the interventions had impacted on their performance as well as changed their attitudes towards their own disability and made them realize their optimal physical, mental and social potential.

Most restrictions in participation were perceived in the domains Family role, Autonomy outdoors and Work and education. Typical symptoms characteristic of late effects of polio are muscle weakness, muscle fatigue, pain and general fatigue, and these impairments influence walking ability and can increase the need for a mobility aid as well as instrumental support. This, in turn, probably explains why the persons perceived most restrictions with their participation in more physically demanding activities, such as heavy housework, repairs and upkeep of the home, and going on trips and holidays.

There was a relationship between the 5 domains for perceived participation and the 9 items for perceived problems with participation. However, the strengths of the relationships clearly indicates that perceiving insufficient participation is not the same as perceiving problems in participation and, conversely, sufficient participation may not be the same as that the person perceives no problem with participation.

Access to instrumental support was most strongly associated with severe problems with participation. Persons who answered that they did not have adequate access to instrumental support, as well as those who received support and answered that it was sufficient, were more likely to experience problems with their participation than those who did not receive support and did not need it. In addition, men were more likely to perceive severe problems with participation. The importance of social support, including instrumental support, for participation has also been described in other groups of people, both men and women, with disabilities (9, 25-30). Support from other people can overcome different barriers, both in the physical and social environment, as well as enhance a disabled individual's experiences of participation (28, 29). Furthermore, the social network members can provide both emotional and instrumental support (27) and motivation and ability to participate in daily activities (26). This implies that persons with late effects of polio who feel they have sufficient instrumental support in their daily lives have a greater possibility to participate in activities according to their preferences compared with those who feel that they do not receive sufficient support.

The sample size ($n = 160$), the relatively high response rate (77%) and the similarity between the responders and non-responders makes it reasonable to believe that the results can be generalized to other persons with late effects of polio in

Table IV. Univariate and multiple logistic regression (odds ratios) of a set of independent variables related to severe problems with participation in persons ($n = 160$) with late effects of polio

Factor	Univariate analysis (OR, 95% CI)	Multivariate analysis* (OR, 95% CI)
Sex		
Female	1.00	1.00
Male	2.28 (1.17-4.43)	4.94 (2.01-12.14)
Age	1.01 (0.98-1.05)	1.00 (0.96-1.05)
Marital status		
Cohabiting/married	1.00	1.00
Single	1.80 (0.91-3.57)	2.12 (0.91-4.91)
Use of mobility aids		
No mobility aid	1.00	1.00
Walking aid	1.38 (0.63-2.99)	0.90 (0.34-2.40)
Wheelchair	2.90 (1.23-6.87)	1.56 (0.53-4.59)
Access to instrumental support		
No support needed	1.00	1.00
Sufficient support	2.88 (1.35-6.12)	4.54 (1.75-11.78)
Insufficient support	9.16 (2.46-34.12)	13.41 (2.99-60.11)

*Nagelkerke R Square of the multiple logistic regression, including 154 persons, was 0.27.

CI: confidence interval; OR: odds ratio.

Sweden. Even though the IPA has been found to be stable across different countries for other populations (31), we cannot assume that similar results will be obtained from persons with late effects of polio in other parts of the world. Moreover, a limitation with the logistic regression in the present study is that the dependent variable was dichotomized based on the summed scores of reports of severe problems with participation, that only some independent variables were used and that other variables may have had a confounding influence on the independent variables used in the analyses. Future research therefore needs to examine more independent variables and their association with specific areas of participation.

Regardless of the results, this study raises some important questions: can we expect full participation among every person with a disability and should the goal of rehabilitation be full participation? Does the use of an instrument such as the IPA really assess "perceived participation", as it is defined in the ICF classification, and can we really capture this broad concept? The distinction between "activity" and "participation" in the ICF classification is not entirely clear and part of the assessment may be the person's performance of daily activities rather than his or her "lived experiences of involvement in their life situation" (1). As participation is considered such an important part of rehabilitation, this area holds potential for future research, and studies evaluating both the short-term effects of various rehabilitation interventions on participation and the long-term outcome are highly desired.

In conclusion, our data show that persons with late effects of polio generally can perceive sufficient participation with no or minor problems in various aspects of participation and that support from other people is an important factor for their perception of severe problems with participation. These findings imply that rehabilitation programmes for persons with late effects of polio need to focus on areas of participation that are perceived as a problem by these persons, and promote access to a supportive environment to enhance their participation.

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