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LIFE SATISFACTION IN PERSONS WITH LATE EFFECTS OF POLIO

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ABSTRACT

Aim: To assess satisfaction with life as a whole and with ten domains of life satisfaction in Swedish persons with late effects of polio, to describe the relationship with sex, age, marital status, use of mobility aids and self-perceived needs of instrumental support, and to compare the level of life satisfaction with a Swedish reference sample.

Method: A cross-sectional study of 160 persons with verified late effects of polio answered a postal questionnaire including the Life Satisfaction Questionnaire (LiSat-11).

Results: A majority were to some degree satisfied with life as a whole and with all the ten domains of life satisfaction. Satisfaction with life as whole was not related to any of the sociodemographic or disability related factors and these factors had few relations to the ten domains of life satisfaction. The respondents were significantly less satisfied with life as a whole and with vocation, leisure, sexual life, activities of daily living, and somatic and psychological health compared to the Swedish reference sample, but were significantly more satisfied with economy and contacts with friends.

Conclusion: Men and women with late effects of polio, regardless of age, marital status or disability, can experience a reduced life satisfaction. This emphasises the need to identify potential gaps between these persons' aspirations and achievements in life and carry out appropriate rehabilitation interventions to enhance their life satisfaction.

Key words

Postpoliomyelitis syndrome; Quality of life; Rehabilitation; Disability evaluation

INTRODUCTION

The importance to identify patients' subjective contentment with life, commonly referred to as 'life satisfaction', is emphasised in the rehabilitation of chronic disabilities and in outcome research (Bränholm, Eklund, Fugl-Meyer, & Fugl-Meyer, 1991; Fugl-Meyer, 1993; Fugl-Meyer, Bränholm, & Fugl-Meyer, 1991; Post, de Witte, & Schrijvers, 1999). Satisfaction with life as a whole and with different domains is a result of an individual's adaptation process and reflects the degree to which an individual perceives that his or her aspirations (or goals) and achievements have been met (Bränholm, et al., 1991; Fugl-Meyer, 1993; Fugl-Meyer, et al., 1991). Thus, life satisfaction is a generic concept without any explicit relation to medical conditions (Fugl-Meyer, Melin, & Fugl-Meyer, 2002). By making comparisons between people with disabilities and with the general population the impact of a chronic disability on life satisfaction can be detected. Such comparisons are needed as low levels of life satisfaction are not necessarily related to medical conditions but have also been detected in the general population. The importance of making investigations in different countries has also been emphasised (Fugl-Meyer, et al., 2002), as diverse cultures and living conditions can influence life satisfaction.

Late effects of polio, also referred to as post-polio syndrome, is a chronic disabling condition that appears in a majority of those with an acute poliomyelitis infection after decades of stability and is estimated to be one of the most common neuromuscular conditions around the world (Trojan & Cashman, 2005). The late effects commonly involve fatigue, muscle weakness, pain (Farbu et al., 2006; Halstead, Gawne, & Pham, 1995; Trojan & Cashman, 2005), and reduced activity and participation (Larsson Lund & Lexell, 2008, 2009a; Thoren-Jonsson & Grimby, 2001; Willen, Thoren-Jonsson, Grimby, & Sunnerhagen, 2007). Even if the need to consider life satisfaction is well-known, only a few studies (Burger & Marincek, 2000; Kemp & Krause, 1999) have examined it in people with late effects of polio and no study has assessed it in Swedish men and women with late effects of polio. In a study of Slovenians with late effects of polio (Burger & Marincek, 2000), a significantly decreased satisfaction with life as a whole and with the domains of activities of daily living (ADL), work and contacts with friends were reported. A similar pattern of reduced life satisfaction was found in an American study of people with late effects of polio that were compared with a non-disabled control group (Kemp & Krause, 1999). When it comes to how different factors influence life satisfaction, it has been shown that an increasing number of new problems related to late effects of polio negatively influence satisfaction with the domains ADL and contacts with friends (Burger & Marincek, 2000). Increased number of

problems with participation in life situations has also been found to affect satisfaction with life as a whole and several domains of life satisfaction (Larsson Lund & Lexell, 2009b) together with the psychosocial variables family functioning and attitudes towards disability (Kemp, Adams, & Campbell, 1997).

In Sweden, there exist population based reference values for life satisfaction, based on sample of 2533 men and women between 18 and 65 years of age (Fugl-Meyer, et al., 2002; Melin, Fugl-Meyer, & Fugl-Meyer, 2003). This enables clinicians and researchers to compare healthy individuals to those with chronic disabilities. In this nationally representative Swedish sample (Fugl-Meyer, et al., 2002; Melin, et al., 2003), 70% of the respondents were very satisfied or satisfied with life as a whole. The majority (77-95%) were also very satisfied or satisfied with their ADL, family life and partner relationship, and psychological and somatic health. A somewhat smaller proportion (54-57%) was satisfied with vocation, leisure and sexual life. This research has also shown that a multitude of factors influences life satisfaction. Being a first generation immigrant, not having a steady partner and not being in good health influence life satisfaction negatively, but age is of minor importance and gender only influences life satisfaction marginally.

As our knowledge about life satisfaction and the relationship with different factors is limited in people with late effects of polio, both in general and in Swedish men and women in particular, further studies of this population is needed. The aim of this cross-sectional study was to assess satisfaction with life as a whole and with ten domains of life satisfaction in Swedish persons with late effects of polio, to describe the relationship with sex, age, marital status, use of mobility aids and self-perceived needs of instrumental support, and to compare the levels of life satisfaction with the Swedish reference sample.

METHODS

Sample

Potential respondents with late effects of polio were obtained from the database in a rehabilitation clinic in a university hospital in the south of Sweden. All persons had been clinically examined, their new symptoms (after a period of functional stability) described and an electromyogram (EMG) in the upper and lower limbs had been recorded as verification of their prior polio. They had thereafter completed an individualised, goal-oriented, comprehensive interdisciplinary rehabilitation program and had been offered to take part in the clinic's life-long follow-up program. A total of 208 persons were contacted and 160 (77%)

gave their informed consent to participate in the study. Of the remaining 48 persons, 25 responded that they did not want to take part, 21 persons did not respond at all, and 2 persons were omitted as their questionnaires were incomplete. Data on these individuals' life satisfaction in relation to perceived participation have been published previously (Larsson Lund & Lexell, 2009b).

Questionnaires

A letter was sent to the potential respondents that included the Life Satisfaction Questionnaire (LiSat-11) and a questionnaire to obtain information about the respondents' sex, age, marital status, vocational situation, use of mobility aids and self-perceived needs of instrumental support in ADL. The use of mobility aids had three response options: use of wheelchair, use of walking aid or no use of mobility aid. The question about self-perceived needs of instrumental support in the areas of self-care, housework and leisure had two response options: having instrumental support and no need of instrumental support.

LiSat-11 (Fugl-Meyer, et al., 2002) is a self-administrated questionnaire that assesses global satisfaction with life in one item and domain-specific satisfaction in ten items. The six response levels are: very satisfied; satisfied; rather satisfied; rather dissatisfied; dissatisfied; and very dissatisfied. LiSat-11 is an extension of LiSat-9, where both validity and reliability have been shown to be adequate (Bränholm, et al., 1991). LiSat-11 has a stable construct and has been found to be valid for the population at large (Fugl-Meyer, et al., 2002; Melin, et al., 2003).

Statistics

Relative frequencies were calculated for the six response levels for the 11 items of LiSat-11. Responses on each of the items were then dictomised as 'satisfied' (very satisfied and satisfied) and 'not satisfied' (from rather satisfied to very dissatisfied), in agreement with the developer of LiSat-11 (Fugl-Meyer, et al., 2002). As LiSat-11 is an ordinal scale (with six categories), non-parametric statistics were used to analyze the data. To detect differences in levels of life satisfaction by sex, age, marital status, use of mobility aids and need of instrumental support, cross-tabulations and chi-square test were applied. Finally, the level of life satisfaction was compared with the Swedish reference sample (Fugl-Meyer, et al., 2002; Melin, et al., 2003) using Chi-square tests.

RESULTS

Of the 160 respondents, 52% were women and 48% men; there was no significant difference in relation to the 48 non-respondents (65% women and 35% men). The respondents' mean age was 68 years (SD 9.5, range 30-86 years), with no significant difference compared to the non-respondents (mean age 70 years, SD 8.9, 53-82 years). A majority of the respondents were married or cohabited (68%), needed instrumental support in their ADL (53%), used mobility aids (39% walking aid and 23% wheel chair) and were retired (61%). One fourth worked full or part time and the remaining (14%) had a temporary or permanent disability pension.

Of the respondents, 45% were satisfied (very satisfied or satisfied) with life as a whole, 47% rather satisfied and only 8% dissatisfied to some degree (Table I). Three quarters or more were very satisfied or satisfied with contacts with friends, family life and partner relationship. The majority were also very satisfied or satisfied with economy, ADL and psychological health. On the other hand, only about a quarter were to some degree satisfied (very satisfied or satisfied) with their sexual life and somatic health.

Table I. Percentages (%) of self-reported levels of life satisfaction in 160 Swedish persons with late effects of polio

	Very satisfied	Satisfied	Rather satisfied	Rather dissatisfied	Dissatisfied	Very dissatisfied
Life as a whole (n:158)	12	33	47	6	1	1
Vocation (n:142)	10	34	39	8	5	4
Economy (n:157)	14	38	31	12	4	1
Leisure (n:157)	10	29	38	18	4	1
Contacts with friends (n:158)	33	42	18	3	3	1
Partner relationship (n:120)	54	32	6	3	1	4
Sexual life (n:141)	8	19	31	11	13	18
Family life (n:138)	45	39	12	3	1	-
ADL (n:160)	18	41	29	9	3	-
Somatic health (n:157)	6	18	38	26	9	3
Psychological health (n:157)	23	37	25	12	2	1

*The number of respondents that answered the different items of LiSat-11 is given in brackets.

A series of analysis to detect statistical differences in sub-groups of the sample (Table II) showed that differences were present among some of the ten domains of life satisfaction but not on the overall life satisfaction domain. The men were significantly more satisfied with economy than the women, and the women were significantly more satisfied with leisure than the men. No differences in life satisfaction were found between those in working-age and those being retired. Those who were single reported significantly lower levels of satisfaction with contacts with friends, family life and partner relationship than those who lived together with a partner. The three groups of use of mobility aids differed significantly on one item: ADL. Those who had instrumental support had significantly lower level of satisfaction with economy, ADL and somatic health compared to those with no need of instrumental support.

Table II. Differences in self-reported levels of life satisfaction by sex, age, marital status, use of mobility aids and need of instrumental support in Swedish persons with late effects of polio (n:160). Values for each item and group are percentages (%) of very satisfied and satisfied, dichotomised as ‘satisfied’ in agreement with the developer of LiSat-11 (Fugl-Meyer et al., 2002).

	<i>Sex</i> Men vs women (n:76/84)	<i>Age</i> 30-64 vs 65-86 years (n:57/103)	<i>Marital status</i> Single vs cohabiting or married (n:52/108)	<i>Use of mobility aids</i> Wheelchair vs walking aid vs no aid (n:36/62/61)	<i>Need of instrumental support</i> Having vs no need (n:82/72)
Life as a whole	41/50	46/45	37/50	47/44/48	45/48
Vocation	48/41	44/45	44/44	47/40/47	44/48
Economy	62/43 *	47/55	42/57	40/49/62	41/66 *
Leisure	30/47 *	39/39	47/35	34/36/43	40/40
Contacts with friends	75/76	72/74	65/80 *	65/77/79	73/80
Partner relationship	90/82	88/86	44/93 ***	73/91/92	81/93
Sexual life	25/29	32/24	16/31	24/26/30	24/31
Family life	87/81	88/82	47/94 ***	70/88/89	80/ 90
ADL	63/55	61/57	48/64	39/52/77 ***	39/81 ***
Somatic health	25/23	25/24	24/24	23/23/27	16/ 33 *
Psychological health	55/65	56/62	54/62	54/69/55	60/61

Chi-square test was used to test for differences between groups.
Significance is represented by * (p<0.05) and *** (p<0.001).

The comparison between the respondents with late effects of polio and the Swedish reference sample (Fugl-Meyer, et al., 2002) (Table III) showed that the respondents were significantly less satisfied with life as whole and with six of the other ten domains of life satisfaction. The respondents were, on the other hand, significantly more satisfied with economy and contacts with friends than the Swedish reference sample.

Table III. Comparison of self-reported levels of life satisfaction in Swedish persons with late effects of polio and the Swedish reference sample (n=2533). Values for each item and group are percentages (%) of very satisfied and satisfied, dichotomised as ‘satisfied’ in agreement with the developer of LiSat-11 (Fugl-Meyer et al., 2002).

	Swedish persons with late effects of polio ¹	Nationally representative Swedish sample	Significance level
Life as a whole	45	70	***
Vocation	44	54	***
Economy	52	39	***
Leisure	39	57	***
Contacts with friends	75	65	***
Partner relationship	86	82	NS
Sexual life	27	56	***
Family life	84	81	NS
ADL	59	95	***
Somatic health	24	72	***
Psychological health	60	81	***

¹The number of respondents that answered the different items of LiSat-11 is presented in Table I.

Chi-square test was used to test for differences between the groups.

Significance is represented by *** (p<0.001). NS represents ‘not significant’.

DISCUSSION

The analysis of the level of satisfaction with life as whole and with the ten domains of life satisfaction in 160 Swedish persons with late effects of polio showed that a majority were, to some degree, satisfied with life as a whole and with all ten domains of LiSat-11, but

significantly less satisfied with life as whole and with six of the other ten domains of life satisfaction in comparison with the Swedish reference sample. Furthermore, satisfaction with life as whole was not related to any of the investigated socio-demographic (sex, age, marital status and vocational situation) and disability related factors (use of mobility aids and need of instrumental support), and only some of the other ten domains of LiSat-11 were related to the investigated factors.

The lower level of satisfaction with life as a whole and with six of the ten domains in LiSat-11 compared with the Swedish reference sample (Fugl-Meyer, et al., 2002) indicate that persons with late effects of polio have decreased life satisfaction in relation to the general population. This is in line with results from other countries (Burger & Marincek, 2000; Kemp & Krause, 1999) using a similar design. However, some studies have concluded that late effects of polio does not affect psycho-social well-being (Ahlstrom & Karlsson, 2000) and that mainly physical aspects are affected (Kling, Persson, & Gardulf, 2000). The reason for this is not entirely clear, but can be related to the instrument used to assess their subjective contentment with life.

The lower levels of life satisfaction among the persons with late effects of polio should be treated with some caution as the Swedish reference sample (Fugl-Meyer, et al., 2002) was in the age range of 18-64 years whereas the 160 persons with late effects of polio were 30 to 86 years of age. Yet, the proportions of individuals being 'satisfied' in the reference sample is similar to another Swedish reference group (n=223) aged 25-81 years (Bränholm, Lundmark, Månsson, & Fugl-Meyer, 1996). Furthermore, a larger proportion of those with late effects of polio lived alone and only a small proportion worked in comparison with the reference sample, where only five percent were on sick-leave (Melin, et al., 2003). It is also important to note that the influence of the polio infection on life satisfaction was not investigated, so further studies are therefore needed to detect the influence of late effects of polio per se on life satisfaction.

Several studies of people with late effects of polio (Kling, et al., 2000; Nollet et al., 1999; Nollet, Beelen, Twisk, Lankhorst, & De Visser, 2003; Nollet et al., 2002; On, Oncu, Atamaz, & Durmaz, 2006; Thoren-Jonsson, Hedberg, & Grimby, 2001; Willen, et al., 2007) have evaluated health-related quality of life (HRQL), i.e., the influence of current health status on overall functioning. Although HRQL is a relevant concept and suitable in measuring needs and effects of disease related interventions in rehabilitation (Fugl-Meyer, et al., 2002; Kind, 2001), the concept has a clearly different conceptual background than life satisfaction. Thereby, results from studies of life satisfaction and HRQL are not comparable. HRQL

investigations tend to be negatively influenced by the health status (Fugl-Meyer, et al., 2002), and comparison will be made in the forthcoming discussion whenever possible.

A large majority (80%) reported that they were rather satisfied or satisfied (level 4 and 5; cf. Table I) with life as whole. This is similar to the mean value of 4.1 in a study of late effects of polio in Slovenia (Burger & Marincek, 2000). Studies of HRQL (Kling, et al., 2000; On, et al., 2006; Thoren-Jonsson, et al., 2001) have reported that persons with late effects of polio describe that their physical status is most affected. In the present sample, the respondents were also most dissatisfied with their somatic health, compared to the other domains of life satisfaction. This is not unexpected as late effects of polio often mean a significant reduction of physical capacity influencing all aspects of daily living. The large proportion of dissatisfaction with sexual life, found in the present sample, has also been found in studies of other neurological health conditions (Bränholm, et al., 1996), and can, again, be related, to some degree, to their physical functioning.

The finding that those with late effects of polio were significantly more satisfied with economy than the Swedish reference sample is somewhat surprising and difficult to explain. However, a majority of them was not working and had different forms of support from society, such as disability pension or old-age pension. Many had also worked up to their retirement and consequently had a reasonably good economy. Partner relationships and family life were the only two domains that were not significantly affected in those with late effects of polio and a similar pattern has been found in studies of HRQL in Swedish persons with late effects of polio (Kling, et al., 2000) as well as other neurological health conditions (Bränholm, et al., 1996). From our clinical experience these persons are not more affected psychologically than the general population, i.e., do not have more depression and anxiety. As they acquired their polio in their childhood and then more or less recovered, they have had the possibility to live without a disability or a limited degree of disability for many years which have helped them to a rich social life.

Overall, there were few differences in life satisfaction for the selected socio-demographic and disability related factors. The result that sex differences were only found for two domains is not surprising, as sex had no major impact on life satisfaction in the Swedish reference sample (Fugl-Meyer, et al., 2002). Even though no age difference was found, increasing age has been found to be positively associated with satisfaction with life as a whole and with a number of domains in the Swedish reference sample. However, our sample was divided only into two age-groups, and this limits the analysis. Those being single reported significantly lower satisfaction in three domains (contacts with friends, partnership and family

life), which differ from the Swedish reference sample where single people generally had significantly lower life satisfaction than those living with a partner.

The disability related factors – use of mobility aids and need of instrumental support – were not significantly related with satisfaction with life as a whole but were significantly related with the domain for ADL (both mobility aids and need of instrumental support), economy and somatic health (only instrumental support). This is somewhat surprising with respect to the earlier discussion that those with late effects of polio have a decreased satisfaction with life. However, the factors studied are not specific for a diagnosis. Future research therefore needs to use specific measures related to late effects of polio to increase our understanding of the relationship between new symptoms and life satisfaction.

The lower level of life satisfaction found in those with late effects of polio imply that their aspirations exceed their achievements, which suggests that their adaptation process may not have been optimal. Research has pointed out the importance to understand the adaption process of people with late effects of polio (Thoren-Jonsson, 2001) and the different strategies used (Jonsson, Moller, & Grimby, 1999). When focusing on life satisfaction to facilitate a successful adaptation in rehabilitation, gaps between goals and achievements can be prevented or narrowed in people with late effects of polio. The finding that life satisfaction in persons with late effects polio is related to their perception of participation (Larsson Lund & Lexell, 2009b) implies that improvement of perceived participation through different rehabilitation interventions may lead to increased life satisfaction. In a recent study (Larsson Lund & Lexell, 2010), we described how persons with late effects of polio experienced the influence of an interdisciplinary rehabilitation programme. The rehabilitation programme was a turning-point in the participant's life and the start of a process of change whereby they acquired new skills which, after about a year, contributed to a different but good life. 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. It is quite likely that this may lead to an increased life satisfaction – studies from our research group are also underway that will describe this.

The response rate of 77% limits the possibility to obtain a complete picture of the studied sample. But, as no significant difference was found between the respondents and the non-respondents age and sex, it is reasonable to assume that similar results would have been found with a higher response rate. Moreover, we only examined the relationship between life satisfaction and a few other factors in a cross-sectional study design and other factors

could have had a confounding influence. More research is therefore needed to determine how different factors influence life satisfaction in people with late effects of polio.

In conclusion, the results show that a majority of people with late effects of polio report some degree of satisfaction with life as a whole and the ten domains of life satisfaction in LiSat-11. In comparison with the Swedish reference values, though, persons with late effects of polio reported significantly lower level of life satisfaction. Thus, men and women with late effects of polio can experience a reduced life satisfaction in comparison with a non-disabled population. This emphasises the need to identify potential gaps between these persons' aspirations and achievements in life and carry out appropriate rehabilitation interventions to enhance their life satisfaction.

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