

Original**FACTORS ASSOCIATED WITH QOL OF POLIO SURVIVORS IN JAPAN**

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Abstract

Objectives: To examine the association of impairments and functional disabilities with health-related quality of life (QOL) of polio survivors in Japan.

Design: Cross-sectional survey.

Settings: Post-polio clinic at a university hospital.

Participants: Polio survivors (N=39) with mild muscle weakness living in the community who voluntarily participated in a health examination for post-polio syndrome.

Interventions: Not applicable.

Main Outcome Measures: The Medical Outcome Study 36-Item Short-Form (SF-36).

Results: Mean score on the physical component scale (43.0) of the SF-36 was lower than that of the mental component scale (52.2), and the vitality subscale for men was higher than that for women. Multivariate analyses identified that the physical dimension of the SF-36 was affected by muscle weakness, while the mental dimension of the SF-36 was affected by personal care activities.

Conclusions: Polio survivors with reduced physical functioning may maintain the mental aspect of QOL using their previous coping strategies to fight functional limitations. Coping with new health problems and adapting to the environment should be examined from not only the physical but also the mental viewpoint of QOL for polio survivors.

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—Key words—

Quality of life, Activities, Polio

Introduction

In the late 1950s, epidemics of poliomyelitis left more than 37,000 survivors with residual weakness in Japan.¹⁾ Although poliomyelitis has become extremely rare in Japan since the introduction of the oral live vaccine in 1961, polio survivors whose neuromuscular symptoms had been stable for 3 or more decades now complain of new symptoms, such as muscle weakness, fatigue and pain, or functional decline. These new health problems are considered as post-polio syndrome (PPS). In recent years, PPS has become a serious issue for Japanese polio survivors. While the epidemics in Japan is following that in USA, the intervention to polio survivors in Japan is behind by approximately 10 years or more. Therefore, in our epidemiological survey of PPS in an area with a population of one million, we found the prevalence of PPS in Japan to be 18.0 per 100,000²⁾. We subsequently published case reports of PPS with workplace disability.³⁾

PPS can lead to significant secondary disabilities and/or handicaps such as termination of gainful employment and inability to continue managing the family and household. In addition, these secondary disabilities interfere with most areas of life and are psychologically debilitating for many individuals who perceive unspecified anxiety and reduced well-being.⁴⁾ However, such psychological issues faced by individuals with a history of polio have not been fully described in terms of health-related quality of life (QOL).

One of the popular instruments for assessing generic health-related QOL is the Medical Outcome Study 36-Item Short-Form (SF-36).⁵⁾⁻⁷⁾ Previous research using the SF-36 with polio survivors has demonstrated a correla-

tion with the 6-minute walk test,⁸⁾ effort-limited treadmill walk test,⁹⁾ and joint and muscle pain¹⁰⁾; however, no correlation has been observed with serum insulin-like growth factor¹¹⁾, which has trophic effects on muscle fibers and peripheral nerves. These findings are useful for managing the disability resulting from PPS, though further information on the state of disability or activities related to the SF-36 are necessary for identifying new strategies and solutions for the psychosocial problems faced by PPS patients.

The present study evaluated the activities measured by the Barthel ADL index (BI)¹²⁾ and Frenchay Activities Index (FAI),¹³⁾ and examined the association of impairments and functional disabilities with the health-related QOL of polio survivors, as measured by the SF-36.

Methods

Research design

We conducted a cross-sectional study on the association of impairments and functional disabilities with the health-related QOL of polio survivors.

Participants

Subjects were recruited from a support group for polio survivors living in the North-Kyushu area of Japan (population: one million) where approximately 340 polio survivors have been identified.²⁾ A total of 39 polio survivors voluntarily joined the health examination for PPS and visited our hospital in October 2003. Subjects were derived from the polio survivors population that we had previously surveyed.²⁾ Inclusion criteria for this study were (1) a history of polio confirmed by subjects' physically disabled persons' certificates, and (2) physical examination findings consistent with past paralytic polio. Most of the polio survivors with paralysis had been issued physically disabled persons' certificates in accordance with the Japanese Welfare of Physically Disabled Persons law.

Data collection

Data for the present study were obtained at the time of presentation to our hospital. The outcome variable was the SF-36 score obtained by interview. Data on the following predictors (independent variables) were also obtained by interview and examination at the time of presentation: current age, sex, age at acute polio, weakness evaluated by manual muscle test of the four extremities and trunk, personal activities evaluated by the BI, and instrumental activities evaluated by the FAI. These independent variables were selected based on our hypothesis that impairment and functional activities would be associated with the SF-36 score. The scales used are described below.

Degree of weakness (weakness index: WI)¹⁴⁾ was estimated on a scale of 0 to 6 during the visit to our hospital. This measure was based on information regarding the degree of weakness in each of the four limbs, respiratory muscle weakness, and speech/swallowing dysfunction. If a limb was unaffected, a 0 was assigned, if mildly weakened (Medical Research Council, MRC grade 4) a 10, if moderately weakened (MRC grade 3) a 50, if severely weakened (MRC grade 1 to 2) a 90, and if completely paralyzed a 100 was assigned. For respiratory muscle function a 50 was assigned for some weakness, and a 100 for weakness requiring the use of a ventilator. For speech/swallowing function, a 50 was assigned for some speech/swallowing dysfunction, and a 100 for complete loss of speech and/or swallowing. The sum of all six figures was then divided by 100 to give a score ranging from 0 to 6 for each subject. Values of the WI were interpreted as follows: normal or mild weakness 0–2.6, moderate or severe weakness 2.61–6.

The self-rated BI¹⁵⁾¹⁶⁾ adopted in this study was derived from Granger's modification¹⁷⁾ of the original BI,¹²⁾ and allowed subjects to evaluate their personal activities of daily life, such as eating, dressing, toileting, bathing and walking independently. It consists of the following two 13-item domains: the self-care index (BI-Sc: eating, grooming, washing and bathing, dressing upper body, dressing lower body, toileting, controlling urination and controlling bowel movements) and the mobility index (BI-Mb: getting in and out of a chair or bed, getting on and off a toilet, getting in and out of bathtub or shower, walking 50 m on level ground, and walking up/down one flight of stairs). Scores range from 0 (complete dependence) to 100 (independence). This self-rated BI has high reliability and validity.¹⁵⁾¹⁶⁾

The FAI was developed by Holbrook to evaluate instrumental activities of daily life and comprises 15 individual activities, such as preparing meals, washing dishes and clothes, cleaning, shopping, hobby, travel, gardening, house/car maintenance, and employment.¹³⁾¹⁸⁾ Each of the 15 items is rated on a 4-level scale from 0 to 3. Scores on all items are summed to give an overall score from 0 (low activity) to 45 (high activity). The FAI is a useful instru-

ment for assessing functional status, and measures instrumental disability and some aspects of being handicapped.¹⁹⁾ In addition, the FAI measures activities which reflect a higher level of independence and increased social skills.²⁰⁾

The SF-36 is one of the popular instruments for assessing generic health-related quality of life (HRQOL), and was designed to represent multidimensional health concepts and measure a range of health states.⁵⁾ It is a self-administered questionnaire containing 36 items in 8 domains: physical functioning (PF), role-physical (RP), role-emotional (RE), bodily pain (BP), vitality (VT), social functioning (SF), mental health (MH), and general health (GH). To calculate the physical or mental dimension score, the 8-scale values were transformed to z scores and aggregated according to established formulas. All domains are scored on a scale from 0 to 100, with 100 representing the best possible health state. A higher score indicates a better QOL, and a change in score of at least 5 is considered clinically significant. Two summary measures of the SF-36 are the Physical Component Summary (PCS) scale and the Mental Component Summary (MCS) scale, which are standardized to have a mean of 50 and standard deviation of 10. Reliability and validity of the SF-36 is well established.^{6,7)} In the present study the SF-36 was self-administered according to the procedures outlined in the administration manual.

Statistical analysis

The StatView statistical analysis program was used for calculation of descriptive statistics, as well as univariate and multivariate analyses. Relationships among the WI, BI-Sc, BI-Mb and FAI were evaluated by Pearson's correlation coefficients. Multiple regression models used SF-36 (PCS or MCS) as the dependent variable and the WI, FAI, BI-Sc, and BI-Mb as independent variables, and evaluated the impact of independent variables on the SF-36.

Results

Some characteristics of the study subjects are presented in Table 1. A total of 39 subjects (21 women and 18 men) completed the requirements of the study. Their mean age was 55.5 years old, 54% of whom were women. The mean age at acute polio onset was 4.2 ± 8.0 years. Of the 39 subjects, 56% (n=22) met the Halstead's criteria for PPS²¹⁾: (1) a history and physical examination compatible with paralytic polio, (2) at least 15 years of functional stability following initial recovery, (3) new muscular weakness or increased symptoms of muscular weakness, and fatigue (muscular and/or general), and (4) no other neurological or medical conditions that could produce weakness and fatigue. Subjects had mild muscle weakness (WI 1.42) mostly in the lower extremities, and were independent in personal and instrumental activities (mean score of total BI: 96.8; mean FAI: 27.5).

The mean PCS score on the SF-36 was lower than that on the MCS, though no significant gender difference was observed (Table 2). Higher scores on the SF-36 were observed for physical role, bodily pain, vitality, social functioning and role emotional. In addition, the mean score for the vitality subscale for men was significantly greater than that for women.

Fig. 1 shows the correlations among independent variables and their impairments and disabilities. A strong positive correlation was observed between the BI-Sc and BI-Mb (straight line in Fig. 1). The FAI showed a significant positive correlation with the BI-Sc and BI-Mb. Significant moderately negative correlations of the WI with activity indices (BI-Sc, BI-Mb, or FAI) were also observed (broken lines in Fig. 1).

Table 1 Characteristic of the subjects (n=39)

Characteristic	Total	Men (n = 18)	Women (n = 21)	p-value (t-test)
Age (yrs)	55.5 ± 8.8	55.2 ± 8.8	54.3 ± 8.4	0.671
WI	1.42 ± 0.86	1.44 ± 0.71	1.40 ± 1.00	0.876
BI-T	96.8 ± 11.3	99.2 ± 2.4	94.7 ± 15.1	0.215
BI-Sc	58.5 ± 6.3	59.9 ± 0.5	57.4 ± 8.5	0.223
BI-Mb	38.2 ± 5.3	39.3 ± 2.0	37.3 ± 6.9	0.230
FAI	27.5 ± 9.2	26.0 ± 9.6	28.8 ± 8.8	0.356

Mean ± SD.

WI: Weakness index (normal or mild = 0-26; moderate or severe weakness = 261-6.0);

BI-T: Total score of Barthel index; BI-Sc: Self-care component of Barthel index; BI-

Mb: Mobility component of Barthel index; FAI: Frenchay Activities Index.

Table 2 Gender differences in 2 components and 8 subscales of SF-36 (n = 36)

	Total	Men (n = 17)	Women (n = 19)	p-value (t-test)
Component				
PCS	43.0 ± 7.9	43.6 ± 3.8	42.5 ± 10.3	0.685
MCS	52.2 ± 10.4	54.2 ± 10.3	50.5 ± 10.5	0.298
Subscale				
Physical functioning	52.7 ± 26.5	57.8 ± 20.5	48.3 ± 30.5	0.272
Physical role	76.3 ± 38.9	84.7 ± 33.4	69.0 ± 42.5	0.214
Bodily pain	71.3 ± 20.4	69.1 ± 18.6	73.2 ± 22.1	0.544
General health	53.3 ± 21.3	54.6 ± 18.8	52.2 ± 23.7	0.729
Vitality	64.6 ± 18.7	71.8 ± 17.1	58.8 ± 18.3	0.032
Social functioning	84.9 ± 19.7	85.4 ± 17.8	84.5 ± 21.6	0.890
Role emotional	72.7 ± 41.8	79.6 ± 39.8	66.7 ± 43.5	0.341
Mental health	69.4 ± 17.8	72.2 ± 18.1	66.8 ± 17.5	0.354

Mean ± SD.

Three cases with missing values were excluded from this analysis.

PCS: Physical component summary scale of the SF-36; MCS: Mental component summary scale of the SF-36.

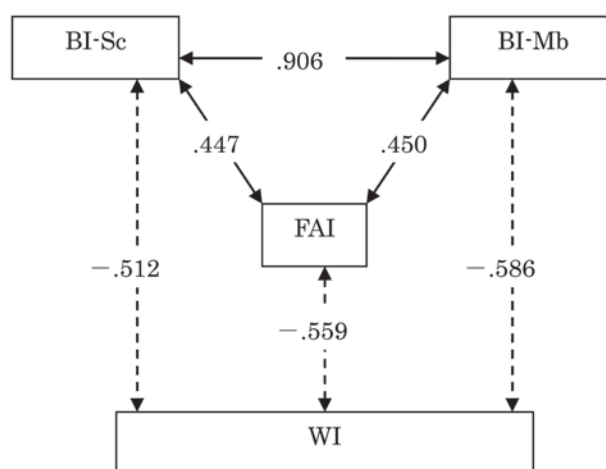


Fig. 1 Correlations among Weakness index, Barthel index and Frenchay Activities Index.

Figures are significant Pearson's correlation coefficients between two variables.

WI: Weakness index; BI-Sc: Self-care component of Barthel index; BI-Mb: Mobility component of Barthel index; FAI: Frenchay Activities Index.

The multivariate models (multiple regression models) that were adjusted for possible confounding by all other factors in the table are presented in Tables 3 and 4. The WI was found to have a significant association with the PCS of the SF-36 (Table 3), while the BI-Sc was significantly associated with the MCS of the SF-36 (Table 4).

Discussions

The present cross-sectional study evaluated the possible association between SF-36 and activities in polio survivors. Two major findings were as follows: (1) impairments such as muscle weakness caused the disability that was evaluated by the BI or FAI (Fig. 1); and (2) in the multiple analyses of the SF-36, muscle weakness influenced the physical dimension of QOL and personal care activities influenced the mental dimension (Tables 3 and 4).

Characteristics of the present sample are similar to those of our original population²⁾: (present sample vs. original population) mean age: 56 vs. 57 years; mean age at acute polio: 4 vs. 2 years; and female subjects: 54% vs. 41%. While subjects in both populations demonstrated mild muscle weakness on the WI, they were highly independent

Table 3 Regression model for SF-36 Physical Component Summary Scale (n = 35)

Variable	Regression coefficient	SE	β	p-value
WI	- 4.53	2.05	- 0.426	0.035
FAI	0.189	0.147	0.208	0.208
BI-Sc	0.562	0.940	0.096	0.554
BI-Mb	0.134	0.538	0.041	0.805
(Constant)	4.617	59.31	4.617	0.939

$R^2 = 0.379$.

Four cases with missing values were excluded from this analysis. WI: Weakness index; FAI: Frenchay Activities Index; BI-Sc: Self-care component of Barthel index; BI-Mb: Mobility component of Barthel index.

Table 4 Regression model for SF-36 Mental Component Summary Scale (n = 35)

Variable	Regression coefficient	SE	β	p-value
WI	1.727	2.818	0.119	0.545
FAI	- 0.041	0.202	- 0.033	0.840
BI-Sc	4.529	1.296	0.570	0.002
BI-Mb	0.901	0.741	0.204	0.234
(Constant)	- 254.1	81.74	- 254.1	0.004

$R^2 = 0.363$.

Four cases with missing values were excluded from this analysis. WI: Weakness index; FAI: Frenchay Activities Index; BI-Sc: Self-care component of Barthel index; BI-Mb: Mobility component of Barthel index.

in terms of personal care (BI-Sc) and mobility (BI-Mb). Comparison of scores of instrumental activities (FAI) in our sample with those in the same age category of the general population²⁰⁾ showed that men in our sample were more active than those in general population (26 vs. 23), whereas women were less active (29 vs. 33).

The mean PCS score (43.0) on the SF-36 was lower than that on the MCS (52.2), which was in the mid-range, and the score for the vitality subscale for men was higher than that for women (Table 2). For polio survivors, PPS is a typical example of secondary impairment, such as a new muscle weakness and fatigue, which leads to secondary disabilities in addition to the original disabilities.²³⁾ These new conditions interfere with most areas of life and some patients may thus perceive unspecified anxiety and reduced well-being in physical performance. However, the polio survivors themselves may not observe or accept the consequences of their reduced function and attempt to maintain their previous mental coping strategies to 'fight' functional limitations, thus demonstrating 'type A behavior'. The mean score on the vitality subscale for men was significantly greater than that for women, which seems to reflect the differences in instrumental activities mentioned above.

One multivariate model for predicting the PCS of the SF-36 revealed that severity of muscle weakness was associated with the reduced physical dimension of QOL (Table 3). This finding is in agreement with Noonan et al⁸⁾ that physical functions such as the 6-minute walk distance are strongly correlated with the PCS of the SF-36. The physical dimension of the SF-36 assesses the degree of limitation experienced in daily physically vigorous activities, which reflect locomotive function. In fact, difficulty of ambulation due to muscle weakness was the most common problem among subjects.

The other multivariate model for predicting the MCS of the SF-36 showed that independence of personal care activities significantly contributed to high scores on the mental dimension of QOL (Table 4). The present findings suggest that independence in daily personal care activities may support and maintain self-esteem. Alternatively personality traits such as 'type A behavior' may result in independence in personal care activities. According to Bruno et al,²⁴⁾ polio survivors push themselves very hard, and are often described as over achievers, demanding per-

fection in all aspects of their personal, professional, and social lives.

Findings from this study must be interpreted in light of the following limitations. First, the majority of the subjects who voluntarily joined this study have mild paresis. Half of the subjects were thought to have developed PPS, but cases with severe muscle weakness were excluded in this study. Therefore, the generalizability of the findings in this study may be limited to mild polio survivors. Second, the cross-sectional design used in the present study prevented examination of the association between changes in QOL and activities over time.

Despite these limitations, our findings that the same factors did not contribute to the different dimension of QOL in polio survivors may provide a new perspective on the support they require. Further follow-up research should aim to clarify whether improving muscle weakness and increasing independence raises QOL for polio survivors.

Conclusions

Our results demonstrate that in a sample of polio survivors with predominantly mild paresis, and who might already have or develop PPS, the physical dimension of QOL was affected by muscle weakness while the mental dimension of QOL was affected by personal care activities. It is important to remember that the different dimensions of QOL were influenced by different factors; therefore, coping with new health problems and adapting to the environment should be considered from not only the physical but also the mental viewpoint of QOL for polio survivors.

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わが国におけるポリオ罹患者のQOLに関連する要因について

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—キーワード—

生活の質, 活動性, ポリオ

【目的】わが国におけるポリオ罹患者の健康関連QOLと、機能障害および活動制限との間の関連性を検討する。

【デザイン】横断的調査。

【設定】大学病院ポストポリオクリニック専門外来。

【対象者】ポストポリオ検診に自主的に参加した在宅のポリオ罹患者39名。

【介入】なし。

【転帰】Medical Outcome Study 36-Item Short-Form (SF-36)。

【結果】SF-36の身体部門スケールの平均値は43.0と

精神部門スケールのそれ(52.2)より低く、下位スケールのうち男性の「活力」の平均値は女性のそれより高かった。多変量解析により、SF-36の身体部門は筋力低下の程度に影響されること、一方、精神部門は個人のセルフケア能力に影響されることが判明した。

【結論】身体機能が低下したポリオ罹患者は、彼らの機能制限に対して戦うという長年の対処方法によってQOLの精神的側面を維持している。彼らの新たな健康問題への対処や環境への適応方法は、QOLの身体面だけでなく精神面からも検討されるべきである。