

# Elderly Norwegian Polio Survivors: Predictors of self-perceived physical and psychological health

Anne-Kristine Schanke, Lillian Vigdis Festvåg, Geir Strømsholm, Johan Kvalvik Stanghelle, Per-Ola Rike, Marianne Løvstad

## ABSTRACT

**Aims:** To explore self-perceived physical and psychological health among elderly Norwegian polio survivors. **Methods:** A questionnaire was distributed to the Norwegian Society of Polio Survivors (LFPS) and others registered with polio in the South-Eastern Norway the last five years (n=1968). A total of 1408 persons responded (72 %). Participants below age 65 years were excluded, leaving 1155 subjects, with a mean age of 72.5 years. The questionnaire covered data from the onset of polio and current demographic, physical, health-related, psychological and social variables. **Lisat 11, Fatigue Severity Scale, Visual**

**Analog Pain Scale and the Resilience Scale for Adults (RSA) were also included. Results:** Concomitant diseases, use of wheelchair, pain and fatigue and a negative perception of the future were associated with unsatisfactory physical health, while feeling psychologically harmed by early treatment and the RSA Factor Perception of self predicted psychological health. Polio survivors demonstrated a capacity for resilience, as they largely reported RSA-scores comparable with young healthy controls. **Conclusion:** Polio survivors represent a pioneer generation of disabled, who have experienced multiple adversities, longstanding disabilities and physical decline. They still need professionals with expertise on aging with polio and an understanding for the challenges they have experienced.

**Keywords:** Physical health, Polio, Post-polio syndrome, Psychological health, Resilience

## How to cite this article

Schanke AK, Festvåg LV, Strømsholm G, Stanghelle JK, Rike PO, Løvstad M. Elderly Norwegian Polio Survivors: Predictors of self-perceived physical and psychological health. *Edorium J Disabil Rehabil* 2018;4:100042D05AS2018.

Article ID: 100042D05AS2018

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doi: 10.5348/100042D05AS2018OA

Anne-Kristine Schanke<sup>1</sup>, Lillian Vigdis Festvåg<sup>2</sup>, Geir Strømsholm<sup>3</sup>, Johan Kvalvik Stanghelle<sup>4</sup>, Per-Ola Rike<sup>5</sup>, Marianne Løvstad<sup>6</sup>

**Affiliations:** <sup>1</sup>Head Psychologist, Department of Research, Sunnaas Rehabilitation Hospital HF, Nesodden, Norway, and Professor, Department of Psychology, University of Oslo, Oslo, Norway; <sup>2</sup>Physiotherapist, Research Assistant, Department of Research, Sunnaas Rehabilitation Hospital HF, Nesodden, Norway, and National Society of Polio Survivors, LFPS, Norway; <sup>3</sup>President of the National Society of Polio Survivors, LFPS, Norway; <sup>4</sup>Research Director, Department of Research, Sunnaas Rehabilitation Hospital HF, Nesodden, Norway, and Institute of Clinical Medicine, Faculty of Medicine, University of Oslo, Oslo, Norway; <sup>5</sup>Psychologist, Department for Evaluation, Sunnaas Rehabilitation Hospital HF, Nesodden, Norway; <sup>6</sup>Psychologist, Researcher, Sunnaas Rehabilitation Hospital HF, Nesodden, Norway, and Department of Psychology, University of Oslo, Oslo, Norway.

**Corresponding Author:** Anne-Kristine Schanke, Sunnaas Rehabilitation Hospital, Bjørnemyrveien 11, State: Bjørnemyr, Norway 1453, Email: anne-kristine.schanke@sunnaas.no

Received: 21 March 2018

Accepted: 13 June 2018

Published: 19 July 2018

## INTRODUCTION

Poliomyelitis is a viral disease of ancient origin. The vast majority (95-99%) of infected individuals remain asymptomatic, while in 1-2 % the disease progresses to a paralytic form [1]. The polio epidemics were among the largest life-threatening conditions during the first half of the 20<sup>th</sup> century. Although the World Health Organization (WHO) declared that poliomyelitis should be eradicated within the year 2000, the polio virus is still present in the poorest areas of the world where vaccination programs do not have sufficient impact [2].

Elderly polio survivors constitute a pioneer generation among people with physical disabilities in the western hemisphere. Throughout their life span from when they contracted polio, typically as children, until today, historical changes such as development in child psychology, medical treatment, as well as cultural norms and attitudes towards people with disabilities, have influenced their lives. Polio trajectories can be divided into five main stages: 1) the acute phase with the onset of paralysis during the 1940s and 50s; 2) the following rehabilitation phase with physical improvement; 3) the long neurologically stable phase of 30-40 years; 4) the occurrence of the late effects in the 1980s and 90s where polio survivors were in their middle age and beyond and 5) ageing with polio. The four first phases have been well described [1]. Several studies have also been conducted during the last decade [3-8]. However, all except one from Pierini and Stuijbergen include samples with a wide age range from 25 to 94 years, with mean age 55 to 70 years [9]. The present study includes subjects aged 65 years and above. To understand some key features formative for the life course of polio survivors, an outline of main empirical findings regarding the four first stages is presented in the following.

### The acute and rehabilitation phase

Most of the polio cases during the 1940s and 50s in the western hemisphere were children. Studies have reported how they responded to hospitalization, characterized by harsh regimes, painful operations and extensive training along with expectations to be “brave, clever and nice”, in accordance with child rearing principles of the time [10-19]. It was widely believed that children adjusted best in hospitals without their parents’ presence, and that “spoiling” should be avoided. Some children felt guilt by burdening their parents by no longer being their “normal child”, which might have contributed to endurance of painful operations and tedious training for many years of their lives [17]. In a review of health practitioners’ views during the epidemics, Westbrook (1996: p. 4) concluded: “Health practitioners at the time of the epidemics attached little importance to the emotions of patients who contracted polio. They grossly underestimated the degree of distress that people, particularly children,

experienced” [20]. On the other hand, according to Yelnik and Laffont (2010: p. 63) “children growing up with physical disabilities, not just polio, who had a proper family and social support, often built-up strong personalities and are used to give their very best just to be like others” [19].

### Adulthood: Striving towards being mainstream citizens

In the following 30-40 years with neurological stability, great efforts were taken among polio survivors to gain independence [19,21]. Western societies were not adjusted to their physical limitations, and the stigmatization and taboos associated with disability, labelled them as invalid or inferior. The sociologist Irving Zola, himself a polio survivor, claimed that to be successful in mainstream society, polio survivors had to downplay the disabilities and their effect on their lives, or even deny their emotional needs [22-24]. Wendell stated that people with disabilities symbolize everyone’s vulnerability, and that in our culture, chronic disease is expected to be linked to misery and unhappiness [25]. Sheer and Luborsky added that the Puritan work ethic contributed to a tendency to disregard or minimize physical limitations and to use self-sufficiency, achievement and productivity as ways to cope with feelings of difference, social rejection and inequality [26].

### The late effects of polio, a second blow and reminder of the past

Physicians and polio survivors originally expected the functional improvements gained in the post-acute phase to be permanent. However, in 1981, a symposium was held in Chicago focusing on a progressive physical decline among middle aged polio survivors. In 1985, the term post-polio syndrome (PPS) was used by the physician and polio survivor Lauro Halstead. PPS was characterized by a gradual or sudden onset of progressive or persistent new muscular weakness and abnormal muscle fatigue with or without generalized fatigue, muscle atrophy and muscle and joint pain [1]. Since the prevalence of PPS varied considerably in the literature, from 15 to 85%, the term late effects of polio became more common. Considerable research on polio has been conducted regarding these late health problems where fatigue was one prevalent symptom [7, 27-35]. At the early stage of the occurrence of the late effects of polio, elevated emotional distress and depression was initially found in cross-sectional studies, but not so in later studies [36-40]. Longitudinal studies also found emotional distress to be reduced over time, which was interpreted as the polio survivors returning to their normal level of psychological functioning as they had time to adapt [34, 41]. Liechty stated that “the length of time between

the onset of new symptoms and psychometric and psychosocial testing may be a performance variable” [42]. When polio survivors experienced the late effects of polio, a wide range of narratives and life stories were presented in the western culture leading to a mutual consciousness of the hardship many had faced during their lives. At the same time, many felt it was a relief to “come out” as polio survivors, and experienced that the reactivation of hidden or repressed memories also offered new opportunities for self-understanding, reconciliation and personal growth [21, 34].

### Aging with polio

Several studies conducted during the past decade have documented an ongoing physical decline among different age groups of polio survivors [3, 4, 7, 8].

Regarding psychological health, Shiri et al. found that longstanding poliomyelitis was associated with decreased psychological health compared to the general population, but that the psychological health of polio survivors was significantly less affected by negative perception of physical health than in healthy controls [6]. The authors states “that these findings may reflect a resilient attitude of polio survivors towards their physical disabilities.” Pierini and Stuijbergen denoted their findings as a paradox, as they in line with Shiri et al. found depressive symptoms to be quite pervasive, yet half the sample reported good or excellent overall self-rated health [9]. They concluded that individual psychological strengths associated with resilience, such as acceptance, self-efficacy, interpersonal relationships, stress management, spiritual growth and positive self-rated health may counter depressive symptoms. This is partly in accordance with Kemp et al. who found that post-polio syndrome has some relation to depression, but that psychosocial variables, especially family support and the survivors` own attitude toward their disability, mediated this effect [43]. Kwon et al found that some of the symptoms of negative affect in the post-polio population may be caused by physical symptoms that are related to the experience of being disabled [5]. Of notice, in these studies, symptoms of pain and fatigue, known to overlap with and mediate depression, were not controlled for Jensen et al. found that pain and fatigue in elderly polio survivors make independent contributions to the prediction of physical and psychological functioning [44]. Regarding sex differences, Vasiliadis et al. found that women with polio are more likely to report muscle and joint pain than men [45]. In summary, the studies reported mixed findings regarding emotional distress, but also with respect to the relationship between emotional and physical symptoms.

### The impact of resilience in coping with late effects of polio

In her paper “Ordinary Magic”, Masten stated that resilience is common in human adaptation [46]. The concept of resilience typically refers to (2009: p.1777), “a pattern of functioning indicative of positive adaptation in the context of significant risk or adversity”, but also the ability of individuals to “bounce back” after stressful events, and re-establish their previous levels of functioning [47]. There is considerable agreement today that the concept of resilience includes three main factors; psychological and dispositional attributes, access to family support and cohesion, and external support systems [48-50]. Thus, this defines resilience as a multifaceted response to being exposed to substantial adversity, which is different from the idea of “ego-resilience”, only including personality traits or characteristics [49].

The concept of resilience derives from long-term longitudinal studies of high-risk children in the 1970s, with a distal time perspective from the onset of the stressor [51-53]. Later, the concept migrated into adult psychology. Adult studies of resilience, usually with a follow-up from one to five years, have identified different trajectories after severe adversity, with a resilient trajectory being the most common [54-59].

To the authors` knowledge, no longitudinal studies of children include institutionalized or hospitalized children, although deprivation and hospitalization of children had been debated [60-62]. A study by Schanke et al. explored the subjectively and retrospectively perceived impact of childhood hospitalization following polio upon later psychological well-being [63]. Twenty-seven percent reported to feel psychologically harmed by the early treatment. As mentioned, two polio studies have focused on a five year follow up after the onset of the late effects of polio, and have traits in common with the adult resilience research tradition [34, 41].

### Aims of the current study

The primary aim of the current study was to explore how a large sample of elderly persons above 65 years of age with long-standing poliomyelitis perceives their physical and psychological functioning, as well as their psychosocial situation. Descriptive data are reported in terms of 1) demographic characteristics, 2) data from the acute and rehabilitation phase after onset of polio, 3) current physical characteristics and health related symptoms, and 4) current psychological and social characteristics. The secondary aim was to investigate whether health-related symptoms, such as fatigue, pain and psychosocial characteristics, predicted current perceived physical and psychological health.

## MATERIALS AND METHODS

### Participants

In January 2014, a questionnaire was distributed to all registered members of the National Society of Polio Survivors (LFPS) (n=1998), and non-members of LFPS with a polio diagnosis registered by the South-Eastern Norway Health Authority the last five years (n=152). At the same time, the web-link was opened (www.tns-gallup.no/polio2014), and the survey was advertised on social media, resulting in 23 additional responders. A reminder was forwarded by mail to non-responders.

A total of 2173 persons were approached for participation in the main study (Figure 1), of which 1968 persons fulfilled the inclusion criteria. A total of 1408 persons, wherein 958 women (68 %) and 450 men (32 %) responded. Reasons for exclusion were not meeting the inclusion criteria, i.e. members of LFPS without polio diagnosis (n = 150), and returning the questionnaires unanswered for reasons not known (n = 55). The response rate was 72 %. After excluding persons below the age of 65 years and those not reporting sex or age, the present study sample consisted of 1155 subjects (Figure 1).

### The Instruments

The study is based on a mailed questionnaire consisting of 87 items covering demographic, medical and psychological data from the acute, rehabilitation and late phase of polio. The questionnaire was designed by the National Society of Polio Survivors in collaboration with researchers, and was based on an earlier survey from 1994 [63, 64]. The questionnaire included various assessment scales, where the following have been included in the current paper:

(1) *Quality of Life*: Two questions from the quality of life scale Lisat -11 [65] were included, asking how the respondents perceived their physical and psychological health on a 7-point scale ranging from “very unsatisfactory” to “very satisfactory” including the category “not relevant”.

(2) *Concomitant Diseases*: A questionnaire containing 19 dichotomized questions (Yes/No) regarding concomitant diseases was derived from a large-scale Norwegian population study, providing an estimate of the number of concomitant diseases (range 0-19) [66].

(3) *Resilience*: The Resilience Scale for Adults (RSA) [67, 68], is a self-report scale designed to measure factors associated with resilience in three domains; dispositional, social and external resources. The scale is amongst the resilience scales with the best psychometric properties [69]. RSA consists of 33 items grouped into 5 factors; 1) Personal strength contains two primary factors: 1A) Perception of self, defined as own current strengths and abilities, 1B) Perception of future, defined as exploring beliefs about opportunities for realizing future plans and goals, 2) Social competence, 3) Family cohesion 4)

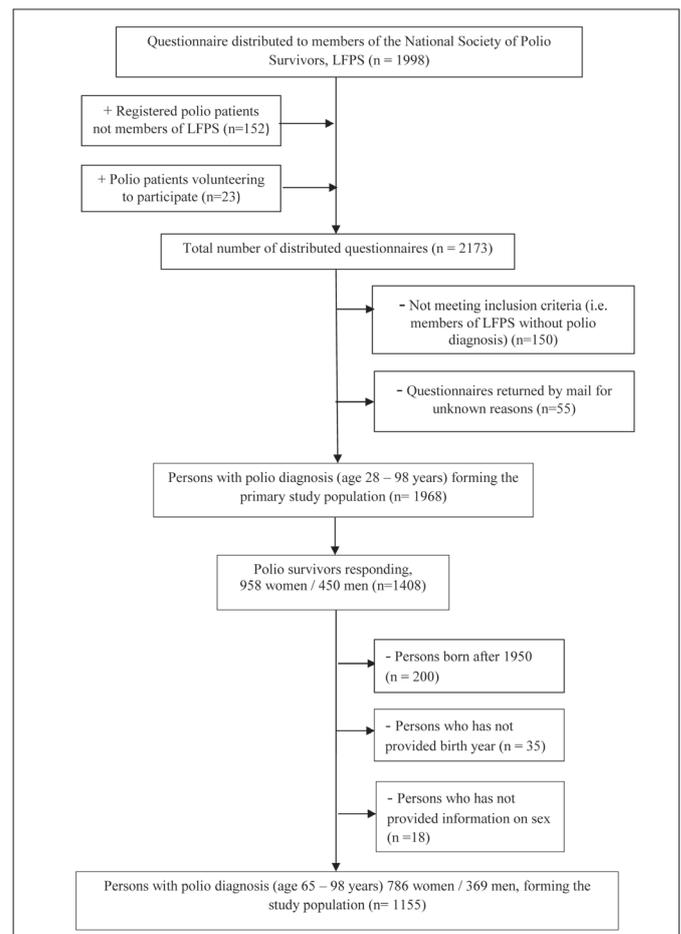


Figure 1: Flow chart.

Social resources and 5) Structured style. Each item is scored along a five-point semantic scale, the total score ranging from 33 to 165. Since Factor 1A, 1B, factor 2 and 5 all include personal factors, while factor 3 and 4 assess family support and socially available resources, the scale focuses most on personal traits.

(4) *Pain*: The respondents were asked to estimate mean pain over the last week on a Visual Analogue Scale, ranging from 0 = no pain, to 10 = unbearable pain.

(5) *Fatigue*: The Fatigue Severity Scale (FSS) was originally designed to measure fatigue experienced by persons with sclerosis multiplex, including a list of 9 statements assessing perceived fatigue [70]. Each statement is rated on a scale from 1=“strong disagreement” to 7=“strong agreement”. The individual score is the mean of the numerical responses to the nine statements, i.e. a maximum score of 7. In accordance with Lerdal et al, the cutoff score of severe fatigue should be scores > 5, and moderate fatigue corresponds to scores between 4.0–4.9 [71].

(6) *Body mass index (BMI)*: BMI is calculated as (measure weight in kilograms/measure height in meters squared). The normal range is between 22-24 (lower limit) and 27-29 (upper limit). To compensate for age-

related reduced height in elderly, the normal range for BMI is higher in people over 65 years [72].

## Statistical analysis

Results were analyzed with IBM SPSS Statistics version 25 (Armonk, New York, US). Differences between genders were tested with Chi-Square for dichotomous variables, and t-tests for continuous variables. Chosen level of significance was  $p < .01$  or  $p < .001$ . The Spearman's Rank Order Correlation ( $\rho$ ) was used to investigate associations between perceived physical and psychological health (Lisat-11). Logistic regression was performed to ascertain the effects of age, sex, marital status (living alone (yes/no)), education level, total number of concomitant illnesses, use of wheelchair, use of respiratory aids, need of help for personal hygiene, use of respiratory aids and wheelchair, pain, fatigue, and the five resilience factors from RSA. Regression analyses were performed to predict the likelihood that participants were satisfied or dissatisfied with their mental and physical health, respectively. In order to handle the data statistically, the dependent variables from Lisat-11 were dichotomized from the original 6-point scale into responses where 1–3 were coded as 1 (unsatisfactory), while responses 4–6 were coded as 0 (satisfactory). The predictor variable "need of help for personal hygiene" was dichotomized, responses indicating no need of help were coded as 0, while responses indicating help with hygiene were coded as 1.

In the tables total numbers of respondents ( $n=$ ) and numbers of responding men/women are provided for each variable.

## RESULTS

### Demographics

The study group consisted of 786 women and 369 men with a mean age of 72.5 years (range 65–98) years.

In total, 41 % were 65–69 years, 26 % 70–74 years, 16% 75–79 years, and 17 % were 80 years or older. There were significant sex differences in years of education, employment and marital status, where women had fewer years of education and lower employment levels. Significantly more men were married or cohabitants (Table 1).

### Data reported from the early onset of polio

Mean age for contracting polio was 6.6 years with no significant sex differences. Thirty-seven percent were younger than 4 years, 43% between 4 and 10 years, and 20% were above 10 years. Significantly more men

reported to have been hospitalized during the acute and rehabilitation phase, but there were no significant sex differences in mean duration of hospitalization. A total of 58 % of the subjects reported that they were rarely or never visited by parents, and 25 % experienced that the early treatment had harmed them psychologically, with no significant sex differences (Table 2).

### Current physical characteristics and health related symptoms

There were no significant sex differences regarding body parts affected by polio, but women used significantly more orthopedic aids, wheelchairs and other devices, possibly because more women than men were living alone. The mean number of concomitant health problems or diseases was two. The study group had a mean BMI equal to 26, which is in accordance with normative data even without correcting for age [72]. Mean FSS scores corresponded to moderate fatigue, with women reporting significantly more fatigue than men. The study group reported extensive muscle and joint pain, women significantly more than men. Women also used significantly more analgesics, sleep medication and sedatives than men, more women than men were smoking, while men had a higher consumption of alcohol than women (Table 3).

### Current psychosocial characteristics

Men and women both reported scores on the RSA that are largely in accordance with normative data although the normative group was younger [68] with the lowest scores on Perception of future.

Furthermore, 87 % reported their psychological health to be satisfactory, while 59% perceived their physical health as satisfactory. Although no sex differences were reported in psychological health, significantly more women reported need of professional help due to psychological problems. Regarding access to social support, the subjects reported to have several close friends. Despite this, 51% felt lonely sometimes or often (Table 4).

Table 5 displays the results from the Spearman's Rank Order Correlation ( $\rho$ ) used to investigate the associations between perceived physical and psychological health (Lisat-11) and number of concomitant illnesses, need of assistance with activities of daily living (ADL) pain fatigue (FSS total score), and resilience (RSA total score and the RSA subscales). Due to the high number of respondents, even small correlations reach statistical significance. The strongest associations were seen between perceived physical health and fatigue and perceptions of future, i.e. lower levels of fatigue and positive perceptions of future were associated with better physical health. Further, positive perceptions of self and future (RSA 1A and 1B) were associated with satisfactory

psychological health. Associations between perceived psychological health and number of concomitant illnesses, total number of ADL, pain and fatigue were classified as negligible, i.e. <0.3 (Table 5).

### Prediction of physical health (Lisat)

The logistic regression model was statistically significant ( $X^2 (18, N = 533) = 90.35, p < .001$ ). As a whole, the logistic regression model explained 38.7% (Nagelkerke R squared) of the variance in physical health status, and correctly classified 75.0 % of the cases. Five of the independent variables made a unique statistically significant contribution to the model, namely total number of concomitant illnesses, use of wheelchair, pain, fatigue and the RSA subscale 1B - Perception of future. Increased number of diseases, use of wheelchair, increased levels of pain and fatigue and more negative perception of the future were associated with unsatisfactory physical health (Table 6).

### Prediction of psychological health (Lisat-11)

The full model containing all predictors was statistically significant ( $X^2 (20, N = 433) = 90.35, p < .001$ ). As a whole, the model explained 42.6 % (Nagelkerke R squared) of the variance in psychological

health status, and correctly classified 91.5 % of the cases. Surprisingly, none of the current physical characteristics such as pain, fatigue or total number of concomitant diseases were related to perceived psychological health. As shown in table 7, only two of the independent variables made a unique statistically significant contribution to the model, namely feeling psychologically harmed by early treatment and RSA Factor 1A (Perception of self). The strongest predictor was “Psychologically harmed by early treatment” (yes/no), with an odds ratio of 0.18. This indicated that respondents who reported to be psychologically harmed by treatment were more likely to report unsatisfactory psychological health. Furthermore, more positive perceptions of self, i.e. higher scores on RSA 1A, was related to better perceived psychological health, all other factors in the model being controlled for (Table 7).

When differences between the age groups 65–74 years and 75+ were compared, we found that significantly more of the persons above 80 were living alone and had a tendency to feel lonelier (Table 8).

## DISCUSSION

The primary aim of the current study was to explore how a large sample of elderly persons with long-standing

Table 1: Demographic characteristics

	Total	Men	Women	p-value/Chi-square
Sex: n (%)	1155	369 (32)	786 (68)	0.000
Age: mean (SD) (n = 1155) (range)	72.5 (6.6) (65–98)	72.3 (6.2) (65–90)	72.5 (6.8) (65– 98)	0.321
Education: % (n = 1071/344/727 )				0.000
1–9 years	22	16	25	
10–12 years	53	51	55	
> 12 years	25	33	21	
Employment:% (n = 1023/322/701)				0.000
Work, full time	3	6	2	
Work, part time	2	2	3	
Disability pension	22	19	24	
Retirement	67	70	69	
Other *	3	6	2	
Marital status: % (n = 1132/363/769)				0.000
Married /cohabitant	64	80	56	
Single	36	20	44	
Other **	1	1	1	

Values are represented as % or mean (SD); [range]. SD = standard deviation. Numbers of respondents (n=), men/women, are given for each variable.

\* Answers that cannot be categorized and which are not included in further analyze.

\*\*Answers dichotomized from the categories unmarried, cohabitant/married, widow /widower, divorced, other.

Table 2: Data from early onset of polio

	Total	Men	Women	p-value/Chi-square
Age at onset of polio: years (SD) (n = 1137/359/778)	6.6 (5.9)	6.6 (5.8)	6.7 (6.0)	0.734
Age at onset of polio: Age categories				X <sup>2</sup> = 1.22, p = 0.545
Under 4 years, % (n = 420/139/281)	37	39	36	
4–10 years, % (n = 486/145/341)	43	40	44	
Older than 10 years, % (n = 231/75/156)	20	21	20	
Hospitalized acute phase *: % (n = 699/240/459)	61	65	58	0.001
Duration: Months, mean (SD) (min–max)	9 (11.5) (0–112)	10 (12.1)	9 (11.1)	0.349
Hospitalized rehab phase *: % (n = 342/122/220)	30	33	28	0.321
Duration: Months, mean (SD) (min–max)	16 (16.2) (1–204)	15(12.1)	16 (18.1)	0.321
Visit by parents during hospitalization: (n = 737/245/492)				
Often, %	42	44	41	
Seldom/never, %	58	56	59	

Values are represented as % or mean (SD); [range]. SD = standard deviation. Numbers of respondents (n=), men / women, are given for each variable.

\* Answers dichotomized from the categories “if hospitalized, give number and years and months” and “No, was not hospitalized”.

Table 3: Current physical characteristics and health related symptoms

	Total	Men	Women	p-value/ Chi-square
<b>Body parts affected by polio:* %</b>				
Legs / hips (n = 1024/334/690)	73	77	71	0.152
Arms /shoulder (n = 836/291/545)	46	48	45	0.102
Spine / back (n = 799/272/527)	40	39	41	0.736
Abdomen / chest (n = 769/269/500)	32	31	33	0.665
Respiratory muscles(n = 761/268/493)	29	29	29	0.626
Pharyngeal muscles (n = 739/260/469)	17	13	20	0.113
Number of concomitant health problems / diseases: (n = 1155/369/786) mean (SD) (min-max)	2,0 (1.6) (0–16)	1.7 (1.5) (0–9)	2.1 (1.7) (0–16)	0.006
<b>Use of technical aids: %</b>				
Orthopedic aids / walker (n = 905/312/593)	77	71	79	0.007
Wheelchair manual and electric (n = 905/905/312/593)	42	34	45	0.001
Ventilator or other respiratory aids (n = 810/297/513)	14	14	15	0.470
Other aids (n = 836)	26	17	32	0.000
Need of help for personal hygiene: yes % (n = 942/319623)	10	8	11	0.032
<b>Other health related characteristics:</b>				
BMI total: ( n = 1089/361/728) mean (SD) (min-max)	26.3 (4.9) (10.5–64.5)	26.6 (5.3) (13.6–64.5)	26.2 (4.8) (10.5–56.8)	0.156
FSS:(n = 910/300/610) mean (SD)	4.7 (1.5)	4.3 (1.5)	4.9 (1.5)	0.000

Table 3: (Continued)

	Total	Men	Women	p-value/ Chi-square
Pain that hampers function in daily life: ** % (n = 1041/321/720)	68	56	74	.000
Pain VAS-scale 1–10***: (SD) (n = 1070/338/732)	4.3 (2.5)	3.4 (2.5)	4.7 (2.4)	.000
<b>Regularly use of medication: %</b>				
Analgesics, % (n = 987/305/682)	20	12	24	.000
Sleep medication,% (n = 919/296/623)	17	13	19	.000
Sedatives, % (n = 868/284/584)	8	5	10	.000
Smoking: yes % (n = 1111/352/759)	15	11	17	.000
Drinking alcohol once a week or more frequentl: % (n = 1106/354/752)	36	46	31	.000

Values are represented as % or mean (SD); [range]. SD = standard deviation. Numbers of respondents (n=), men / women, are given for each variable. BMI total: Body Mass Index (weight/height 2), FSS = Fatigue Severity Scale, VAS-scale = Visual Analog Scale  
\* (some, moderate, complete paresis) \*\* (some to considerably degree) \*\*\* (mean pain last week)

Table 4: Current psychosocial characteristics

	Total	Men	Women	p-value/Chi-square
RSA total (SD) (n = 816/278/538)	3.9	3.9 (0.5)	3.9 (0.5)	0.360
Factor 1 A: Perception of self (6 items)	3.9	4.0 (0.7)	3.9 (0.8)	0.013
Factor 1 B: Perception of future (4 items)	3.2	3.4 (1.0)	3.2 (0.9)	0.009
Factor 2: Social competence (6 items)	3.8	3.8 (0.8)	3.8 (0.8)	0.218
Factor 3: Family cohesion (6 items)	4.1	4.1 (0.7)	4.1 (0.7)	0.308
Factor 4: Social resources (7 items)	4.3	4.3 (0.7)	4.4 (0.6)	0.048
Factor 5: Structured style ( 4 items)	3.6	3.7 (0.7)	3.6 (0.7)	0.126
<b>Self-reported health:</b>				
My physical health: % (n = 1075/345/730)				0.080
Satisfactory	59	63	57	
Unsatisfactory	41	37	43	
<b>My psychological health: % (n = 1075/345/730)</b>				
Satisfactory	87	89	86	0.776
Unsatisfactory	12	10	13	
Psychological problems in need of professional help: % (n = 997/330/667)	18	11	21	0.000
Psychologically harmed by the early treatment*: % (n = 1060/339/721)				
Yes	25	22	26	0.102
No / do not know	75	78	74	
<b>Social support:</b>				
Number of close friends: mean (SD) (n = 1027/330/697)	8.7 (7.1)	9.1 (8.0)	8.5 (6.8)	.184
Feeling lonely sometimes/often: % (n = 1102/354/748)	51	44	55	.013

Values are represented as % or mean (SD); [range]. SD = standard deviation. Numbers of respondents (n=), men / women, are given for each variable. RSA: Resilience Scale for Adults.  
\* (some to considerably degree)

Table 5: The associations between perceived physical and psychological health and number of concomitant illnesses need of assistance with activities of daily living, pain, fatigue and resilience.

	Perceived physical health		Perceived psychological health	
		N		N
Perceived physical health (Lisat-11)			0.293**	797
Perceived psychological health (Lisat-11)	0.293**	798		
Need of assistance with ADL (yes/no, range 0–11)	0.276**	1088	0.153**	1075
Number of concomitant illnesses	0.183**	1088	0.150**	1075
Pain (VAS-scale)	0.326**	1038	0.195**	1026
Fatigue (FSS total score)	0.415**	906	0.185**	903
RSA total (n = 816/278/538)	-0.251**		-0.294**	
Factor 1 A: Perception of self (6 items)	-0.194**	976	-0.341**	970
Factor 1 B: Perception of future (4 items)	-0.415**	986	-0.327**	980
Factor 2: Social competence (6 items)	-0.109**	933	-0.150**	929
Factor 3: Family cohesion (6 items)	-0.134**	960	-0.169**	956
Factor 4: Social resources (7 items)	-0.087**	969	-0.162**	966
Factor 5: Structured style (4 items)	-0.154**	1015	-0.163**	1009

Numbers of respondents (n=) are given for each variable. Lisat-11 = Life Satisfaction Questionnaire, ADL = Activities of daily living, VAS-scale = Visual Analog Scale, FSS = Fatigue Severity Scale, RSA: Resilience Scale for Adults.

\*\* Correlation is significant at the 0.01 level (2-tailed)

Table 6: Prediction of perceived physical health

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for Exp(B)	
							Lower	Upper
Age	-0.031	0.019	2.600	1	0.107	0.970	0.935	1.007
Sex	0.011	0.236	0.002	1	0.964	1.011	0.637	1.604
Marital status (living alone - yes/no)	0.037	0.253	0.022	1	0.883	1.038	0.632	1.705
Education level	0.074	0.270	0.074	1	0.785	1.076	0.634	1.827
Total number of concomitant illnesses	0.192	0.076	6.323	1	0.012	1.212	1.043	1.407
Pain (VAS- scale)	0.152	0.050	9.239	1	0.002	1.164	1.055	1.283
Fatigue (FSS)	0.359	0.086	17.481	1	0.000	1.432	1.210	1.694
RSA 1A - Perceptions of self	0.148	0.192	0.589	1	0.443	1.159	0.795	1.690
RSA 1B - Perceptions of future	0.867	0.167	27.034	1	0.000	0.420	0.303	0.583
RSA 2 - Social competence	0.051	0.179	0.081	1	0.776	1.052	0.741	1.495
RSA 3 - Family cohesion	0.311	0.223	1.941	1	0.164	0.733	0.473	1.135
RSA 4 - Social resources	0.326	0.262	1.547	1	0.214	1.385	0.829	2.313
RSA 5 - Structured style	0.026	0.168	0.024	1	0.876	1.027	0.738	1.427
Use of respiratory aids	0.636	0.334	3.617	1	0.057	0.529	0.275	1.020
Use of wheelchair	0.508	0.236	4.636	1	0.031	0.602	0.379	0.955
Need of help for personal hygiene	0.532	0.408	1.703	1	0.192	0.587	0.264	1.307
Constant	2.114	1.819	1.350	1	0.245	8.279		

N=533. Numbers of respondents (n=) are given. VAS-scale = Visual Analog Scale, FSS = Fatigue Severity Scale, RSA: Resilience Scale for Adults.

Table 7: Prediction of perceived psychological health

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
							Lower	Upper
Age	0.032	0.039	0.691	1	0.406	1.033	0.957	1.114
Marital status (living alone - yes/no)	0.829	0.544	2.321	1	0.128	0.436	0.150	1.268
Education level	0.309	0.616	0.252	1	0.616	1.362	0.407	4.556
Use of respiratory aids	0.658	0.684	0.925	1	0.336	1.931	0.505	7.382
Use of wheelchair	0.923	0.487	3.598	1	0.058	0.397	0.153	1.031
Need of help for personal hygiene	0.052	0.737	0.005	1	0.943	1.054	0.248	4.468
Total number of concomitant illnesses	0.076	0.129	0.346	1	0.557	1.079	0.837	1.391
Pain (VAS scale)	0.123	0.112	1.201	1	0.273	1.131	0.908	1.409
Psychologically harmed by treatment	1.725	0.475	13.159	1	0.000	0.178	0.070	0.453
Feeling lonely	0.806	0.493	2.673	1	0.102	0.446	0.170	1.174
Fatigue (FSS)	0.064	0.195	0.107	1	0.744	0.938	0.640	1.376
RSA 1A - Perceptions of self	1.114	0.355	9.839	1	0.002	0.328	0.164	0.658
RSA 1B - Perceptions of future	0.450	0.331	1.847	1	0.174	0.637	0.333	1.220
RSA 2 - Social competence	0.315	0.355	0.788	1	0.375	1.370	0.683	2.747
RSA 3 - Family cohesion	0.190	0.451	0.179	1	0.673	1.210	0.500	2.926
RSA 4 - Social resources	0.059	0.499	0.014	1	0.906	0.943	0.355	2.506
RSA 5 - Structured style	0.282	0.324	0.753	1	0.386	0.755	0.400	1.425
Alcohol consumption	0.750	0.508	2.179	1	0.140	0.472	0.174	1.279
Constant	0.842	3.673	0.053	1	0.819	2.320		

N=431. Numbers of respondents are given. VAS-scale = Visual Analog Scale, FSS = Fatigue Severity Scale, RSA: Resilience Scale for Adults.

Table 8: Psychosocial and physical characteristics in different age categories

	65–69 years (41 %)	70–74 years (26 %)	75–79 years (16 %)	>80 years (17 %)	Sig.
Marital status (cohabitant/married) % (n=1132)	69	70	60	37	0.000
Feeling lonely (yes/no) % (n=1090)	47	51	57	59	0.025
RSA total (SD) (n=814)	3.9 (0.53)	3.9 (.52)	3.9 (.51)	3.9 (0.51)	0.516
Number of close friends (SD) (n=1036)	8.4 (6.0)	8.4 (6.9)	10.5 (10.3)	8.2 (6.7)	0.006
Satisfactory physical health (yes/no) (n=1088)	58	62	58	55	0.493
Satisfactory psychological health (yes/no) (n=1075)	88	88	92	85	0.284

Numbers of respondents (n=) are given for each variable. Values are represented as % or mean (SD). SD = standard deviation. Numbers respondents for each variable (n=) are given. RSA: Resilience Scale for Adults.

poliomyelitis perceives their physical and psychological functioning, as well as their psychosocial situation. One main finding was that while a large proportion (i.e. 41%) of elderly polio survivors were quite unsatisfied with their physical health; only 12% were unsatisfied with their psychological health. Furthermore, physical and psychological health was not predicted by the same variables, and despite life-long adversity and challenges polio survivors report resilience levels comparable to healthy controls.

When comparing the results with demographic normative data in the elderly Norwegian population, level of education in the study group was somewhat higher or equal to normative data, in line with the high education level among Norwegian polio survivors previously documented [73, 74]. Marital status was also shown to be in accordance with normative data. Women used significantly more analgesics, sleep medication and sedatives than men, also in accordance with normative data on elderly people [75]. Regarding smoking, data from the general elderly population show that 13 %smoke on a daily basis, compared to 15% in the study population. The use of alcohol was similar to the general elderly population with a higher consumption among men [76, 77].

Secondly, when comparing current data regarding the early onset of polio with the Norwegian polio study conducted in 1994, there were only minor differences [63]. Age at onset of polio differed slightly (mean age in 1994 was 7.3 vs. 6.6 in 2014), and more of the respondents in 1994 versus 2014 reported to have been hospitalized in the acute (71 vs. 61%) and rehabilitation phase (42 vs. 30%). However, the proportion reporting that they were rarely or never visited during hospitalization (58%) was quite similar to the 1994 study (57%), and so was the proportion feeling psychologically harmed by the early treatment, with 25% in the present study compared to 27% in 1994. We do not know the number of subjects who participated in both surveys, due to respondent anonymity, but the overlap in answers may reflect how the conditions in the acute phase are typically perceived at hindsight for a large number of Norwegian polio survivors. Festvåg et al. found that the 2014 population reported only minor subjective worsening of health and well-being compared to the 1994 cohort, despite physical deterioration [78]. This is probably due to the fact that when polio survivors in general were confronted with physical decline and emotional distress due to late effects, they made major life style changes and put great efforts into adapting and coping with the situation. The fact that the numbers of those reporting to be in need of professional help for psychological problems were equal in 1994 and 2014 (18%), supports this interpretation [78].

The occurrence of fatigue and pain was explored, as these are debilitating symptoms reported in many polio studies. In this study, mean FSS-scores were in the upper range of moderate fatigue among women (4.9), and in the

lower moderate range for men (4.3), where normative Norwegian data for persons above 60 years is a mean score of 4.2. (4.2 for women and 4.1 for men [71]. Compared to Norwegian polio studies, the present mean FSS-score of 4.7 is lower than both a Norwegian outpatient polio sample (mean 5.6), and an earlier polio survey sample (mean 5.2) [34, 35]. This might reflect reduced daily life demands among elderly polio survivors, resulting in lower subjective experiences of being fatigued. In a recent study on former polio inpatients, the mean FSS-score was higher, 5.4, probably due to differences in selection of the study groups, inpatients and survey respondents [31]. Regarding pain, women reported significantly more pain than men, in accordance with Vasiliadis et al., but interestingly, pain levels did not contribute in explaining psychological health in our study [45]. These findings are contrary to Jensen et al., where pain was associated with depression among polio survivors, which was also found in a study on patients with multi-trauma and spinal cord injuries [44, 79]. In a study of long-term survivors of traumatic spinal cord injury, health related quality of life was decreased, particularly in those with health concerns such as pain [80]. Likewise, van Leeuwen et al. found pain severity to be one of the factors discriminating between low and high life satisfactory trajectories among persons with spinal cord injury [81]. One explanation for this surprising finding might be that polio survivors have learned to cope with pain throughout their lifetime, thus reducing its impact on quality of life, or that studies are not easily comparable due to variation in samples and age groups.

In a study by Friberg et al., a strong association was found between resilience and personal traits such as emotional stability (absence of neuroticism, which resembles Factor 1A, Perception of self and IB, Perception of future) [82]. These two factors are of most interest for clinicians, since those low on emotional stability usually report more symptoms of anxiety and depression, more negative affect and lower self-esteem [83].

When exploring resilience, we found that the RSA-scores were largely comparable to normative data, although these consist of younger healthy persons [68]. One exception was Factor 1B (Perception of future), which was lower in our sample, maybe reflecting a subjective expectation of further physical decline among elderly. RSA Factor 3 Family Cohesion, on the other hand, was higher in the study group (4.1) compared to normative data (3.1). In a study by Friberg et al. where the predictive validity of the RSA was explored experimentally, individuals with high RSA-scores reported less pain and stress [84]. In a study including persons with multi-traumas and spinal cord injuries, RSA IA Perception of self and RSA IB, Perception of future accounted for most variance in health-related quality of life, which seems to be in accordance with the present study [85].

We consider a most interesting finding in the

present study to be that different variables contributed in predicting subjectively perceived physical and psychological health. While higher number of concomitant diseases, use of wheelchair, higher pain and fatigue levels were associated with unsatisfactory physical health, only two of the independent variables, namely feeling psychologically harmed by early polio treatment, and the RSA IA, Perception of self, assessing psychological hardiness, predicted psychological health. This is in accordance with other studies conducted on polio survivors, reflecting a resilient attitude where subjects experience good quality of life despite their physical decline [6, 9, 86, 87]. The description of the life stages of polio survivors outlined in the introduction may further add to the understanding of the results. The elderly polio survivors of today grew up in a society where they needed to downplay their disabilities in order to be part of the mainstream society as adults, and used coping styles such as self-sufficiency and productivity to compensate for their physical disabilities. Furthermore, when the late effects occurred, resilience such as the ability to “bounce back” was put at stake in order to re-establish previous levels of adaptation [49]. Pierini et al. state: “We suggest that for people with the post-polio syndrome, who have spent a lifetime managing the challenges of living with functional limitations, resilience characteristics and responses may be important keys to coping with change” [9].

Finally, as we included only elderly polio survivors in the present study, we wanted to explore how the results fit with research on the adaptation and resilience among elderly in general. According to reviews on resilience in aging, and normative elderly Norwegian data elderly are in general apt to reduce expectations and adjust to physical decline [47, 88-89]. Therefore, contrary to the fact that old age often is associated with multiple psychosocial losses and declining health, research has illustrated an absence of strong declines in subjective-well-being. Ong et al states that “positive emotions may function in the service of well-being, not only by interrupting the ongoing experience of daily distress, but also by averting the delays in adaptation to subsequent stressors [47].” On the other hand, Ong et al. [47] underline the importance of being socially connected, and Luthar states [90] : “resilience rests, fundamentally on relationships”. In a study of 4541 subjects above 60 years, Levasseur et al. demonstrated that resilience, assessed by the ability to cope with adversity, moderates the association between community belonging and social participation [91]. Further, a meta-analytic review by Holt-Lunstad showed that people with adequate or strong social relationships had a 50% increased likelihood of survival, compared to those with weaker relationships [92]. Further, the authors stated that “this influence is comparable to quitting smoking and superior to obesity or physical inactivity” [91]. In the present study, we

found that the majority of the respondents reported satisfactory psychological health, but those who reported feeling lonely were older and not married/cohabitants. Our study further demonstrates resilience among polio survivors, where the extended definition from Luthar, including both dispositional attributes, social support and cohesion, contribute [49]. Further, in accordance with Shiri et al., our study supports their hypothesis that resilience in polio survivors seems to be linked to their ability to block further decline of psychological health, despite the physical decline they experience [6].

However, factors contributing to resilience can change across time. The lowest score on RSA was found on factor IB, Perception of future, probably due to the subjects foreseeing a physical, and perhaps also a cognitive decline, as the process of aging continues. The majority of the study group (67%) is still in the early stage of older adulthood, between 65-74 years, where increased age can make them more vulnerable. A higher number than the elderly Norwegian population in general (25%) [89] felt lonely (51%). This may be due to restrictions in societal participation due to physical disabilities, but also their history of being institutionalized and separated from their families in formative years as children, making them vulnerable to the experience of feeling alienated and psychologically left alone. According to Hansen and Slagsvold, loneliness is associated with health problems and not having a partner [89]. In our study, 20% of the men and 44% of the women were living alone. When differences between the age groups 65-74 years and 75+ were compared, we found that a higher proportion of the older group was living alone, felt lonelier and reported less satisfactory physical health, despite having more close friends, relatively similar psychological health and total score on the RSA.

In conclusion, despite having lived most of their lives with considerable health challenges and demanding life events such as deprivation, hospitalization and being disabled, in this survey, elderly polio survivors documented a capacity for resilience, as they reported scores on the RSA largely comparable to healthy controls.

Halstead outlines that polio survivors have previously been the object of considerable attention among researchers, but not so much today [93]. We wanted to contribute to continue the research tradition. Further research should be conducted on polio survivors throughout their process of aging. They represent a pioneer generation of disabled, and their experiences can add to the understanding of human resilience and adaptation in general, but also provide knowledge of relevance to other diagnostic groups who live with longstanding disabilities.

## Study limitations

The number of polio survivors in Norway is estimated to be approximately 8 - 10 000 persons, where the numbers of persons 65 years or older is not known [64]. Hence, we cannot know for sure whether the participants in this survey are representative of the population. There is probably a bias in that more women than men responded.

In general, questionnaire-based studies have limitations, especially when the subjects are asked to recollect information from the time they contracted polio and until now. Current psychological health, including moods of depression, has probably influenced upon how they perceived their past, but also if they have been exposed to other serious life-events, which was not corrected for. The proportion of missing data is probably due to the questionnaire being extensive to handle for elderly people, but also reflect problems in remembering facts from the past.

## Clinical implications

As clinicians and researchers who have met polio survivors since the time they got the late effects of polio, we do not find the main results surprising. However, there is a challenge in health care professionals meeting the variety of individuals with interest and respect. Further, in clinical work, it is important to question what is the relative part played by polio, lifestyle, natural physiological constitution, new health issues, or natural aging for each person [19]. Time should also be taken to differentiate the individual and unique underlying physical and psychological components causing symptoms of pain, fatigue and emotional distress. Finally, being elderly represents a general human challenge with potential multiple losses, but where polio survivors have the additional experience of early hospitalization and longstanding disability. When the functional decline continues, the feeling of being helpless may reactivate early memories and lead to emotional distress that needs to be respectfully addressed by professionals.

## CONCLUSION

The main conclusion of the present study is that older polio survivors document a capacity for resilience, despite having lived most of their lives with considerable health challenges and demanding life events such as deprivation, hospitalization and being disabled. The study also demonstrates resilience in accordance with the extended definition from Luthar, including dispositional attributes, social support and external resources. dispositional attributes, social support and external resources. Further, in accordance with Shiri et al., our study supports their hypothesis that resilience

in polio survivors seems to be linked to their ability to block further decline of psychological health, despite the physical decline they experience. The study also demonstrates that our study population becomes lonelier than the normal population with increasing age, which might be an additional vulnerability factor, since social connection is so paramount to human health.

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### Acknowledgements

The authors would like to thank TNS Gallup, Jonny Nordøy and Audun Fladmoe. We will also thank the Hunt Study, which is collaboration between HUNT Research Centre (Faculty of Medicine, Norwegian University of Science and Technology NTNU), Nord-Trøndelag County Council, Central Norway Health Authority, and the Norwegian Institute of Public Health. In addition, we thank the board of the National Society of Polio Survivors, LFPS, for collaboration and finally, all polio survivors who have contributed in sharing their experiences in this study.

### Author Contributions

Anne-Kristine Schanke – Substantial contributions to conception and design, Acquisition of data, Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published  
Lillian Vigdis Festvåg – Substantial contributions to conception and design, Acquisition of data, Analysis

and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

Geir Strømsholm – Substantial contributions to conception and design, Revising it critically for important intellectual content, Final approval of the version to be published

Johan Kvalvik Stanghelle – Substantial contributions to conception and design, Revising it critically for important intellectual content, Final approval of the version to be published

Per-Ola Rike – Analysis and interpretation of data, Revising it critically for important intellectual content, Final approval of the version to be published

Marianne Løvstad – Analysis and interpretation of data, Drafting the article, Revising it critically for important intellectual content, Final approval of the version to be published

### Guarantor of Submission

The corresponding author is the guarantor of submission.

### Source of Support

None.

### Consent Statement

Written informed consent was obtained from the patient for publication of this study.

### Conflict of Interest

Authors declare no conflict of interest.

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