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REVIEW

Quality of life assessment scales in polio survivors: a scoping review

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Abstract

Background Quality of life evaluation is essential to explore the effect of paralytic polio on the daily life experience of the polio survivor. Researchers have employed a range of assessment instruments to evaluate quality of life among polio survivors. Hence, to select the appropriate scale, it is crucial to compare the contents and psychometric properties of these instruments.

Purpose This scoping review explores quality of life instruments that are used in polio literature and analyzes their contents and psychometric properties using the Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) criteria.

Method Using the Arksey and O'Malley framework, we conducted a literature search in the following electronic databases Medline, CINAHL, Web of Science, Embase, and Google Scholar to identify relevant studies that focused on quality of life of polio survivors. Of the 88 articles that qualify for full-text screening, 34 studies met our inclusion criteria. Two independent reviewers extracted data from the selected studies via Covidence, a reference manager that allows for blinding of reviews.

Results Most of the instruments included in this review are generic, self-reported, and multidimensional. Despite having mostly adequate psychometric properties, these properties were not evaluated in polio survivors.

Conclusion The information provided in this review could be used to guide instrument selection and identify the need to develop a new tool or to adapt a pre-existing scale for measuring quality of life among polio survivors.

Keywords Polio · Quality of life · Questionnaires · Contents · Psychometrics

Introduction

Quality of life is an important outcome that researchers often employ to measure the success of rehabilitation services for persons with disabilities [1–3]. Globally, about twenty million people or more are living with various disabling sequelae of paralytic polio, which may adversely affect their quality of life [4, 5]. Researchers argue that quality of life lacks a definitive framework for conceptualization and measurement [6–9]. Within polio literature, concepts such as life satisfaction, happiness, subjective wellbeing, health status, and functional status are typically used as surrogates of quality of life [10–18]. Studies on the quality of life of polio survivors have reported various findings, which may likely result from inconsistent operationalization and measurement [12, 14, 18, 19]. Some studies have demonstrated that polio survivors have a good quality of life, which is conceptualized as happiness and satisfaction with relevant domains of life [13, 18, 19]. However, other evidence shows that most polio

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survivors report poor quality of life compared to non-disabled cohorts [12, 14–16, 20, 21].

Quality of life can be associated with a range of health, environmental, and personal factors. For example, some studies have reported a significant positive association between quality of life of polio survivors and health status, health-promoting behavior, physical and mental function, personal relationship, family role, disability attitude, employment, hope, purpose in life, coping style, self-efficacy, and participation [14, 20, 22–24]. On the other hand, evidence has shown a significant negative relationship between quality of life of polio survivors and age, duration of impairment, functional limitation, impaired mental health, comorbidities, and physical and social barriers [23–26]. Although interesting, these findings are based on inconsistent measurement of quality of life using various types of instruments and are therefore difficult to generalize. Moreover, conceptual differences between these instruments could make a comparison of results across the studies problematic.

Quality of life evaluation is paramount to understanding the effect of conditions such as paralytic polio on physical, social, and emotional wellbeing of the individual [6, 8]. Employing a quality of life instrument can provide a comprehensive person-centered approach to evaluate how paralytic polio affects the individuals' daily life experience [27]. Unlike other neurological conditions such as multiple sclerosis and stroke, to our knowledge, there are no disease-specific instruments for evaluating quality of life among polio survivors [28, 29]. Most of the quality of life instruments that are used with polio survivors are either generic measures, for example, the Short Form-36, or other condition-specific scales, for instance, Quality of Life Index- multiple sclerosis version [25, 30]. Thus, it is unclear whether the contents of these instruments truly reflect the relevant aspects of quality of life for polio survivors. Moreover, these instruments need to demonstrate adequate psychometric properties in this population to provide valid and reliable results. Researchers believed that these properties are not necessarily constant and depend largely on context and population among others [31].

Although detailed content comparison of different quality of life instruments in various conditions such as cerebral palsy, stroke, and concussion injury is evident in the literature [27, 32, 33], we could not identify any study that systematically reviews the literature to explore and analyze instruments which are used to evaluate quality of life among polio survivors. We believe that this background information is critical to the selection of the most appropriate instrument among the commonly employed scales in this population. In light of this, we conducted a scoping review of the literature to examine the contents and psychometric properties of commonly employed instruments for assessing quality of life among polio survivors. We aimed to determine specifically, (I) in what instances is quality of life measured for polio survivors and for what research, (II) which instruments do researchers presently use to assess quality of life among polio survivors, and (III) what are the contents and psychometric properties of these instruments?

Method

Based on the purpose of this review, we employed the scoping framework first described by Arksey and O'Malley [34]. This framework is highly recommended by experts for literature synthesis, based on its methodological rigor, flexibility, and transparency [35]. Additionally, the framework provides an avenue for exploring extant literature to identify knowledge gaps. The framework is made up of five steps: (I) identifying the research question, (II) identifying the relevant studies, (III) selecting the studies, (IV) charting the data, and (V) collating, summarizing, and reporting the results. We used this framework to explore the literature on measures of quality of life among polio survivors and synthesize extant evidence on the use, contents, and psychometric properties of these scales. We reported our study based on the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) [36].

Research question

In the first step, we developed our research questions—described above—based on the purpose of the review. Based on these questions, we developed the search terms and focused the search strategy. Due to lack of a standardized and acceptable definition of quality of life, we refrain from employing any of the existing definitions [9]. However, we believe that quality of life is generally subjective and multidimensional in nature [7, 9, 10, 37]. Moreover, the terms 'quality of life' and 'health-related quality of life' are commonly used interchangeably in the literature [9]. To prevent unnecessary exclusion of relevant studies, we considered any study that self-identified as evaluating 'quality of life' or 'health-related quality of life' among polio survivors irrespective of the definition or terminology employed. We adopted the Center for Disease Control and Prevention (CDC) definition for paralytic polio, which defines it as an acute viral infection that affects motor neurons in the brainstem and spinal cord, leading to acute flaccid paralysis [38, 39]. We also defined a polio survivor as an individual who developed paralytic sequelae following primary polio infection irrespective of whether the individual has a post-polio syndrome or not [39].

Search strategy

In the second step, we searched the literature and identified the relevant studies using various combinations of search terms presented in Table 1. The search terms were reviewed by a health science librarian and we further refined the search strategy iteratively based on the librarian recommendation. We conducted the search from the inception of the databases to December 31, 2017. We searched the following databases: Medline, CINAHL, Web of Science, EMBASE, and Google Scholar. We varied the search terms based on the database in order to generate maximum hits. Beyond the academic databases, we performed a manual electronic search of the websites of relevant polio organizations, specifically Post-Polio Health International, Polio Australia, and the British Polio Fellowship. We selected these organizations because they are the only ones we could identify that report research papers on their websites. We also manually searched the references of the studies we identified in the initial database search. Table 1 provides further details of our search strategy.

Selection of studies

Eligibility

In the third step, we selected the relevant studies based on predetermined inclusion and exclusion criteria. We included studies that assessed quality of life of polio survivors, employed a quantitative quality of life scale, were published in English, and a full-text article was available online. We excluded studies that employed other populations, studies that were not related to polio, studies that did not use a quality of life scale, literature reviews, commentaries, editorials, opinion papers, and qualitative studies.

Screening

From the initial search, we identified 1228 articles from the database search and 61 articles from polio organization websites and manual reference search. Following the removal of 136 duplicates, two authors (SS and CO) compiled the remaining 1153 articles into a citation manager (Mendeley) and imported the library into a reference manager (Covidence). SS and CO independently screened the title and abstract of the 1153 articles via Covidence, which allowed for blinding of reviewers thereby minimizing author bias. When in conflict about whether an article satisfied the inclusion criteria, we met, discussed, and reached consensus or consulted with a third reviewer (HA) who served as an arbitrator. This process resulted in the identification of 88 articles that potentially met our inclusion criteria for full-text review. SS and CO independently screened for the full text of the 88 articles. Similar to the title and abstract screening, we resolved our conflicts through discussions and consultation with a third party (HA). Overall, we identified 34 articles for inclusion. Figure 1 provides a graphical representation of the review process.

Table 1 Search strategy

Database	Search term
MEDLINE	(Poliomyelitis OR Postpoliomyelitis syndrome) AND (Quality of life OR Personal Satisfaction OR Happiness) AND (Self-Assessment OR Outcome Assessment OR Surveys and Questionnaires)
CINAHL	(Poliomyelitis OR Postpoliomyelitis syndrome OR Polio Survivors) AND (Quality of life OR Personal Satisfaction OR Happiness OR Life Purpose) AND (Outcome Assessment OR Evaluation OR Scales OR Questionnaires)
WEB OF SCIENCE	(Polio OR Poliomyelitis OR Post-polio Syndrome OR Postpoliomyelitis Syndrome OR Polio Survivor) AND (Quality of life OR Health-Related Quality of life OR Subjective Wellbeing) AND (Outcome Assessment OR Scales OR Questionnaire)
EMBASE	(Poliomyelitis OR Paralytic poliomyelitis OR Postpoliomyelitis syndrome OR Polio Survivor) AND (Quality of Life OR Wellbeing OR Life Satisfaction OR Happiness) AND (Outcome Assessment OR Questionnaire OR Indicator)
GOOGLE SCHOLAR	(Paralytic Polio OR Poliomyelitis OR Post-polio Syndrome) AND (Polio Survivors OR Post-polio Subjects) AND (Quality of Life OR Health-Related Quality of Life OR Subjective Wellbeing OR Life Satisfaction) AND (Measurement OR Assessment OR Evaluation OR Instruments OR Scales OR Questionnaires OR Outcome measure) AND (Indicators OR Determinants)
POLIO ORGANIZATIONS (Post-Polio Health International, Polio Australia, and British Polio Fellowship)	Poliomyelitis OR Post-polio Syndrome AND Polio Survivors OR Post-polio Subjects AND Quality of Life OR Health-Related Quality of life OR Subjective Wellbeing OR Life Satisfaction AND Measurement OR Assessment OR Evaluation AND Instruments OR Scales OR Questionnaires OR Outcome measure

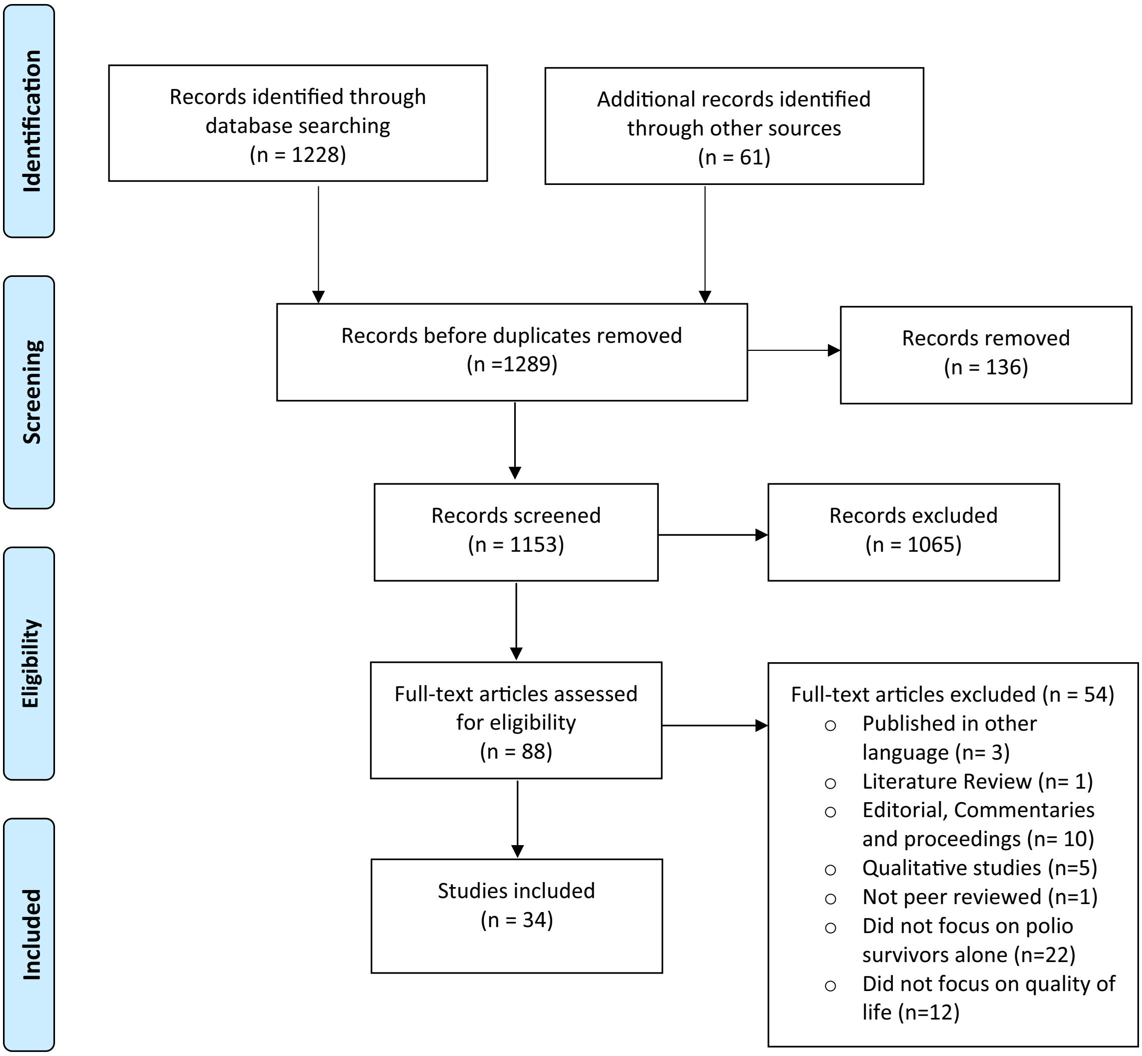

Fig. 1 PRISMA flow chart of included studies

Agreement for inclusion of studies

From the initial title and abstract screening of the 1153 articles, we observed a good agreement for inclusion into full-text screening, with a Kappa Coefficient of 0.90. In the full-text screening of the remaining 88 articles, we also observed a good agreement for inclusion into the study, with a Kappa Coefficient of 0.85. This shows that overall there was a good agreement between the reviewers.

Charting the data

In the fourth step, we developed our data extraction form based on the goals of our review. We extracted relevant information about the scales of quality of life. We conducted the data extraction in an iterative process. Two authors (SS and CO) met, developed the data extraction form, and discussed the key themes to extract in order to answer the research question. To ensure consistency in the data extracted, we independently charted the first ten studies and compared the results. In cases of discrepancies, we reached consensus through discussion or consultation with a third party (HA). Overall, we observed a good agreement on the type of data to be extracted in the first ten articles (kappa coefficient = 0.92). SS and CO independently charted the remaining 24 articles (12 articles each).

We thematically analyzed the domains of the instruments inductively and organized them into categories. Moreover, we assessed the reported psychometric properties of the instruments—internal consistency, reliability, content validity, construct validity, criterion validity, measurement error, and responsiveness—using the Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) checklist [40–42]. The COSMIN checklist provides well-established set of criteria for appraising and selecting outcome assessment instruments, based on evidence of psychometric evaluation [42]. We extracted information about the reported properties of the instruments from the articles we identified through the database search and manual reference search. For each of the instruments, we rated the measurement property as either adequate or not adequate. Table 2 provides details of the psychometric evaluation of the included instruments.

Collating, summarizing and reporting the results

In the fifth step, we collated, summarized, and reported our findings descriptively and analytically using figures and tables. We synthesized the data in accordance with the following steps; analyzing the data—descriptive numerical and qualitative thematic analyses—reporting the findings, and discussing implications of the findings.

Results

Descriptive characteristics of the studies

Among the included studies, twenty-three articles used a cross-sectional design, ten articles employed an experimental design, and one article used a follow-up design. Overall, the articles provided data from twelve countries (Sweden, US, Turkey, Israel, Canada, Nigeria, Netherlands, Japan, Ireland, Italy, Korea, and Denmark). Moreover, twenty were published between 2000 and 2009, while the remaining fourteen were published between 2010 and 2017. Furthermore, twenty-two articles focused solely on individuals with post-polio syndrome, while the remaining twelve articles focused on both individuals with and without post-polio syndrome. The sample size in the included studies ranged from 14 to 2153 participants. Table 3 summarizes the descriptive characteristics of the included studies.

Use of quality of life instruments

Quality of life instruments are commonly used in cross-sectional and experimental studies as either primary or secondary outcome measures. Moreover, they are also employed in follow-up designs that track changes in individual status. In cross-sectional studies, quality of life scales are used to evaluate quality of life and determine its relationship with the relevant sociodemographic and health-related variables. In experimental designs, quality of life instruments are used to assess change in quality of life following an intervention. While in follow-up design, quality of life scales are used to measure changes in quality of life over time as a result of exposure to certain conditions. Tables 3 and 4 provide detailed information about the use of quality of life scales in polio literature and the purpose of their use.

Table 2 Psychometric evaluation

Internal consistency	We rated internal consistency as adequate when the Cronbach alpha is ≥ 0.7, not adequate when the criterion was not met, and not applicable (NA) when internal consistency was not reported
Reliability	We considered reliability as adequate when the Intraclass Correlation Coefficient (ICC) or weighted Kappa is ≥ 0.7, not adequate when the criterion was not met, and not applicable (NA) when reliability was not reported
Content validity	We considered content validity as adequate when the target population was involved in the development of the scale, not adequate when the criterion was not met and not applicable (NA) when the property was not reported
Construct validity	We rated construct validity as adequate when the factors explained at least 40% of the variance, not adequate when the criterion was not met, and not applicable (NA) when construct validity was not reported
Criterion validity	We rated criterion validity as adequate when the correlation with a criterion instrument(s) is ≥ 0.50, not adequate when the criterion was not met, and not applicable (NA) when criterion validity was not reported
Measurement error	We rated measurement error as adequate when the Smallest Detectable Change (SDC) or Limit of Agreement (LoA) is less than Minimal Important Change (MIC), not adequate when the criterion was not met, and not applicable (NA) when measurement error was not reported
Responsiveness	We rated responsiveness as adequate when the correlation with the anchor instrument is ≥ 0.50, not adequate when the criterion was not satisfied, and not applicable (NA) when responsiveness was not reported

Table 3 Descriptive characteristics of studies on Quality of life in Polio Survivors

Author, Year, country	Study purpose	Study design	Study population	Sample size (Male/Female)	Instrument employed
Bertolasi et al. (2013), Italy	To investigate in a single-center randomized control trial whether a single intravenous immunoglobulin (IVIg) course improves short-term outcome in patients with post-polio syndrome (PPS)	Randomized Control Trial	Post-Polio Syndrome	50(25/25)	Short Form-36
Stuifbergen et al. (2005), US	To determine if the explanatory model of health promotion and quality of life developed in earlier studies with persons with multiple sclerosis represented an adequate fit to data provided by a sample of persons with a different chronic neurological condition, post-polio syndrome	Cross-sectional	Post-Polio Syndrome	1549(465/1084)	Quality of life Index-Multiple Sclerosis
Murray et al. (2014), Ireland	To determine the extent of motor fatigue and its impact on mobility and quality of life, in addition to other commonly reported impairments	Cross-sectional	Post-Polio Syndrome	30(15/15)	Short Form-36
Ahlstrom and Karlsson (2000), Sweden	To investigate disability and quality of life in individuals with the characteristic symptoms of post-polio syndrome	Cross-sectional	Post-Polio Syndrome	39(22/17)	Kaasa's Questionnaire, Quality of life profile
Kaponides et al. (2006), Sweden	To analyze changes in muscle strength, physical performance, and quality of life during intravenous immunoglobulin (IVIg) treatment in patients with post-polio syndrome	Open clinical trial	Post-Polio Syndrome	14(8/6)	Short Form-36
On et al. (2005), Turkey	To find out if lamotrigine gives symptomatic relief and enhances quality of life in patients with post-polio syndrome	Randomized Control Trial	Post-Polio Syndrome	30(NA)	Nottingham Health Profile
Skough et al. (2008), Sweden	To investigate the effect of resistance training in combination with oral supplementation with coenzyme Q10 in patients with post-polio syndrome regarding muscle strength and endurance as well as functional capacity and health-related quality of life	Randomized Control Trial	Post-Polio Syndrome	14(6/8)	Short Form-36

Table 3 (continued)

Author, Year, country	Study purpose	Study design	Study population	Sample size (Male/Female)	Instrument employed
Finch et al. (2004), Canada	To determine the reliability and construct validity of an effort-limited treadmill walk test to measure functional ability in subjects with post-polio syndrome in an outpatient post-polio clinic	Cross-sectional	Post-Polio Syndrome	15(7/8)	Short Form-36
Kaka et al. (2011), Nigeria	To assess Quality of Life (QOL), and examine its association with occupation and level of education among polio survivors	Cross-sectional	Polio Survivors	54(45/9)	WHO Quality of life Questionnaire-Brief
Yang et al. (2015), Korea	To assess health-related quality of life in polio survivors (PS) compared with that in the general population in Korea	Cross-sectional	Polio Survivors	120(47/74)	European Quality of life -5 Dimension Questionnaire
Saeki and Hachisuka (2006), Japan	To examine the association of impairments and functional disabilities with health-related quality of life (QOL) of polio survivors in Japan	Cross-sectional	Polio Survivors	39(18/21)	Short Form-36
Legters et al. (2006), US	To examine prevalence of fear of falling (FOF) and decreased balance confidence in individuals with post-polio syndrome (PPS) and to determine whether balance confidence was correlated with health-related quality of life (HRQOL) in this population	Cross-sectional	Post-Polio Syndrome	172(NA)	Short Form-36
Garip et al. (2017), Turkey	To determine the impact of post-polio syndrome on quality of life in polio survivors	Cross-sectional	Polio Survivors	40(24/16)	Nottingham Health Profile
Werhagen and Borg (2013), Sweden	To analyze the impact of pain on quality of life in patients with post-polio syndrome	Cross-sectional	Post-Polio Syndrome	114(47/67)	Short Form-36
On et al. (2006), Turkey	To assess the impact of post-polio-related fatigue on quality of life	Cross-sectional	Polio Survivors	36(15/21)	Nottingham Health Profile
Gonzalez et al. (2006), Sweden	To analyze the clinical effect of treatment with intravenous immunoglobulin given twice at 3-month intervals in patients with post-polio syndrome	Randomized Control Trial	Post-Polio Syndrome	142(50/92)	Short Form-36

Table 3 (continued)

Author, Year, country	Study purpose	Study design	Study population	Sample size (Male/Female)	Instrument employed
Gonzalez et al. (2012), Sweden	To examine the effects of intravenous immunoglobulin (IVIG) on cytokine expression and clinical outcome one year after IVIG treatment	Randomized Control Trial	Post-Polio Syndrome	41(NA)	Short Form-36
Harrison and Stuifbergen (2006), US	To explore the protective effects that finding a purpose in life has on the level of physical and mental impairment and overall quality of life	Cross-sectional	Polio Survivors	2153(667/1486)	Quality of life Index-Multiple Sclerosis
Vreede et al. (2016), Sweden	To conduct a follow-up of the group of patients with sequelae of poliomyelitis. The health of the patients from 1995 to 2012 was evaluated	Follow-up Study	Polio Survivors	60(25/35)	Short Form-36, European Quality of life -5 Dimension Questionnaire
Vasconcelos et al. (2007), US	To determine if modafinil can improve fatigue in patients with post-polio syndrome	Randomized Control Trial	Post-Polio Syndrome	33(12/21)	Short Form-36
Koopman et al. (2016), Netherland	To study the efficacy of exercise therapy (ET) and cognitive behavioral therapy (CBT) on reducing fatigue and improving activities and HRQoL in patients with PPS	Randomized Control Trial	Post-Polio Syndrome	68(31/37)	Short Form-36
Bertelsen et al. (2009), Denmark	To evaluate the outcome of physiotherapy as part of multidisciplinary rehabilitation	Prospective uncontrolled intervention study	Post-Polio Syndrome	50(20/30)	Short Form-36
Adegoke et al. (2012), Nigeria	To investigate and compare the quality of life (QOL) of Nigerian adolescent polio survivors with that of their age- and sex-matched controls	Cross-sectional	Polio Survivors	73(45/28)	Comprehensive Quality of Life Scale-Adolescent
Östlund et al. (2011), Sweden	To examine the characteristics of fatigued and non-fatigued post-polio patients and to define potential subgroups across the fatigue continuum	Cross-sectional	Post-Polio Syndrome	143(51/92)	Short Form-36
Shiri et al. (2012), Israel	To determine the effect of future-oriented coping strategies on the quality of life (QOL) of individuals with post-polio syndrome (PPS)	Cross-sectional	Post-Polio Syndrome	61(31/30)	Short Form-36

Table 3 (continued)

Author, Year, country	Study purpose	Study design	Study population	Sample size (Male/Female)	Instrument employed
Vasiliadis et al. (2002), Canada	To identify predictive and associated factors for muscle and joint pain in postpoliomyelitis syndrome (PPS)	Cross-sectional	Post-Polio Syndrome	126(NA)	Short Form-36
Jacob and Shapira (2010), Israel	To evaluate the perceptions of health and quality of life among a group of polio survivors in Israel and to identify potential activities for improving their quality of life	Cross-sectional	Polio Survivors	101(44/57)	Short Form-12
Kalpakjian and Lequerica (2006), US	To explore quality of life (QOL) in a sample of postmenopausal women with physical disabilities due to polio contracted in childhood	Cross-sectional	Polio Survivors	752(NA/752)	Satisfaction with Life Scale
Jung et al. (2014), Sweden	To investigate the health-related quality of life (QOL) in Swedish patients with post-polio syndrome (PPS), with a focus on sex and age	Cross-sectional	Post-Polio Syndrome	364(133/231)	Short Form-36
Stuifbergen (2005), US	To explore the frequency of selected secondary conditions, factors associated with these conditions, and the relationship between secondary conditions and quality of life among polio survivors	Cross-sectional	Polio Survivors	2153(667/1486)	Quality of life Index-Multiple Sclerosis
Trojan et al. (2001), US	To determine if serum insulin-like growth factor-I (IGF-I) levels are associated with strength, body mass index (BMI), fatigue, or quality of life in postpoliomyelitis syndrome (PPS)	Cross-sectional	Post-Polio Syndrome	112(45/67)	Short Form-36
Oncu et al. (2009), Turkey	To investigate and compare the impact of hospital and home exercise programmes on aerobic capacity, fatigue, and quality of life in patients with post-polio syndrome	Randomized Control Trial	Post-Polio Syndrome	32(12/16)	Nottingham Health Profile
Kling and Persson (2000), Sweden	To investigate and describe the self-rated health-related quality of life and functional status of a group of Swedish patients with post-polio	Cross-sectional	Post-Polio Syndrome	150(64/86)	Swedish Health-Related Quality of Life Questionnaire

Table 3 (continued)

Author, Year, country	Study purpose	Study design	Study population	Sample size (Male/Female)	Instrument employed
Östlund et al. (2008), Sweden	To evaluate vitality and fatigue in post-polio patients, and the relative contributions of physiological and psychological parameters to the level of vitality	Cross-sectional	Polio Survivors	143(51/92)	Short Form-36

NA not available

Measures of quality of life

We identified eleven instruments that have been employed to assess quality of life among polio survivors. Of these instruments, the Short Form-36 (SF36) was the most commonly used scale, employed by twenty articles [12, 30, 43–60]. Following the SF36 was the Nottingham Health Profile (NHP), which was used in four studies [16, 61–63]. Next is the Quality of Life Index (QLI), which was employed in three articles [23, 25, 64]. Subsequently the EuroQoL-5D (EQ 5D), this instrument was utilized by only two studies [15, 56]. The remaining instruments were all employed once in the included studies. Table 4 provides additional information about domains of the instruments, form of administration, approximate completion time, and the list of studies that employed the instruments.

Contents of the instruments

With the exception of the Satisfaction with Life Scale (SWLS), all the identified instruments were multidimensional, consisting of various items, which were categorized into various domains. The frequently included domains were physical, social, and psychological functions. Other dimensions include general health, economic, spiritual, and life condition. Figure 2 provides a pictorial representation of the domains of the instruments.

Reported psychometric properties of the instruments

We identified 35 articles that reported various psychometric properties of the included instruments. Table 5 presents general information about these properties and the articles that reported the properties. Despite the variable scores reported in the various articles, almost all the questionnaires have adequately reported properties (see Table 2 for details of the evaluation criteria). Internal consistency and construct validity were the commonly reported psychometrics, followed by reliability and criterion validity. However, measurement error was not reported in any of the instruments. Most of the psychometric properties were evaluated for the SF36. Conversely, the SWED-QUAL had the least assessed properties and were all reported in one study. For all of the included questionnaires, none of the psychometric evaluations were conducted solely among polio survivors.

Table 4 Quality of life instruments used in polio literature

Instrument	Number of items	Domains	Form of administration	Approximate completion time
Short Form-36 (SF36)	36	Physical Functioning, Role physical, Bodily pain, General Health, Vitality, Social functioning, Role Emotional, and Mental Health	Self or Interviewer-administered	10 to 60 min
Nottingham Health Profile (NHP)	38	Physical mobility, Social isolation, Emotional reactions, Pain, Sleep, and Energy	Self or Interviewer-administered	10 min
Quality of Life Index (QLI)	35	Health and functioning, Social and economic, Psychological and Spiritual, and Family	Self-administered	10 min
EuroQol-5D (EQD5)	5	Mobility, Self-care, Usual activity, Pain/Discomfort, and Anxiety/Depression	Self-administered	5 min
Kaasa's Questionnaire (KQ)	12	Psychosocial wellbeing, Medical side-effects, Activities of daily living, and Physical performance	Self-administered	NA
Quality of life Profile (QP)	44	Life-picture, Life-areas, Problems, and Acceptance	NA	NA
WHOQOL-BREF	26	Physical health, Psychological health, Social relationships, and Environmental	Self or Interviewer-administered	15 min
Comprehensive Quality of life Scale (CQS)	35	Material wellbeing, Health, Productivity, Intimacy, Safety, Place in community, and Emotional wellbeing	Interviewer-administered	45 min
Satisfaction with Life Scale (SWLS)	5	NA	Self or Interviewer-administered	5 min
Swedish Health-related Quality of life Questionnaire (SWED-QUAL)	61	Physical functioning, Role functioning, Emotional wellbeing, Pain, Sleep, Family functioning and General health perceptions	Self-administered	15 min
Short Form-12 (SF12)	12	Physical Functioning, Role physical, Bodily pain, General Health, Vitality, Social functioning, Role Emotional, and Mental Health	Self or Interviewer-administered	5 min

NA not available

Discussion

Various generic and disease-specific quality of life instruments are available in the literature [8]. To prevent duplication and unnecessary development of new scales, it is recommended that users choose from the pool of pre-existing instruments [26]. When selecting the appropriate instrument for a particular purpose, it is relevant to compare the conceptual and psychometric properties of the pre-existing instruments [65]. This review reports on the current state of knowledge about the application, content, and psychometric properties of instruments, which are presently used to assess quality of life among polio survivors. It is anticipated that this information will provide users with deeper insight into the conceptual basis of these scales and enable them to make an informed choice.

Our review shows that quality of life is commonly measured among polio survivors to assess the effectiveness of interventions meant to promote the wellbeing of the individuals [50, 51, 57, 62]. In addition, quality of life is also evaluated to give a snapshot of the individuals' current status [15, 53, 66, 67]. However, it is rarely used to provide information about the individuals' condition over time [56]. This implies the relevance of quality of life in evaluating and monitoring how paralytic polio or interventions may affect the everyday life experience of the individuals. Moreover, these findings point to the need for more follow-up studies that can track the effect of paralytic polio and other related influences on the daily life experience of the individuals for an extended period of time. Additionally, most of the studies focused on individuals with post-polio syndrome. This is anticipated considering that majority are reported from high-income countries that eradicated polio decades ago and the survivors are likely to have developed post-polio syndrome [4]. Thus, there is a need for active research engagement in low- and middle-income countries, especially where paralytic polio

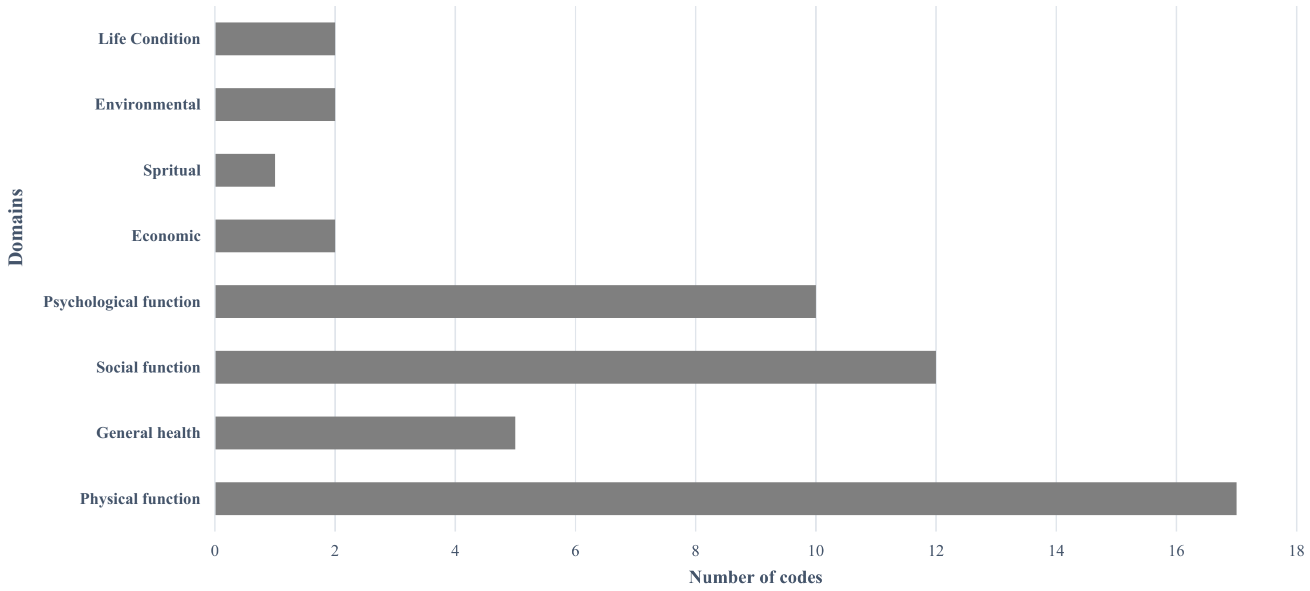

Fig. 2 Domains represented in the instruments

Table 5 Psychometric evaluation of the instruments

Instruments	Reliability			Validity			Responsiveness
	Internal consistency	Reliability	Measurement error	Content validity	Construct validity	Criterion validity	
Short Form-36 (SF36)	Adequate [79, 80]	Adequate [80, 81]	NA	Adequate [79, 82]	Adequate [82, 83]	Adequate [79, 84]	Adequate [80, 80]
Nottingham Health Profile (NHP)	Adequate [85, 86]	Adequate [87, 88]	NA	NA	Adequate [86]	Not adequate [85]	Adequate [88]
Quality of Life Index (QLI)	Adequate [89, 90]	Adequate [91]	NA	Adequate [89]	Adequate [89, 92]	Adequate [89]	NA
EuroQol-5D (EQD5)	Adequate [93]	Adequate [93, 94]	NA	NA	Adequate [94–96]	Adequate [93]	Adequate [93, 96]
Kaasa's Questionnaire (KQ)	Adequate [97]	NA	NA	Adequate [97]	Adequate [98]	NA	NA
Quality of life Profile (QP)	NA	NA	NA	Adequate [21]	NA	NA	NA
WHOQOL-BREF	Adequate [99–101]	Adequate [99]	NA	Adequate [99]	Adequate [99–101]	NA	Adequate [100]
Comprehensive Quality of life Scale (CQS)	Adequate [102–104]	Adequate [103]	NA	NA	Adequate [102]	NA	NA
Satisfaction with Life Scale (SWLS)	Adequate [105–107]	Adequate [105, 108]	NA	NA	Adequate [105–107]	NA	NA
Swedish Health-related Quality of life Questionnaire (SWED-QUAL)	Adequate [109]	NA	NA	Adequate [109]	Adequate [109]	NA	NA
Short Form-12 (SF12)	Adequate [110–112]	Adequate [110–113]	NA	NA	Adequate [112, 113]	Adequate [112]	NA

NA not applicable

cases are still being reported such as Afghanistan, Nigeria, and Pakistan [68].

Furthermore, instruments included in this review are predominantly self-reported scales and consist of items that are grouped into various domains, which include physical, social, psychological, general health, economic, spiritual, and life condition. This implies that quality of life is commonly construed as subjective and multifaceted construct within polio literature, hence multidimensional patient-reported instruments are typically used to measure it. This is consistent with the extant literature, which shows that quality of life is generally subjective, meaning it is based on self-evaluation by the individual, and multidimensional, consisting of various dimensions that the individual considered to be relevant [7–9]. On the other hand, our psychometric evaluation focuses solely on the following properties; internal consistency, reliability, measurement error, content validity, construct validity, criterion validity, and responsiveness. Knowing these properties would guide users' decision when selecting the desired instrument. For example, in addition to validity and reliability, a highly responsive instrument may be considered over a less responsive scale in follow-up studies.

This review shows that the SF36 is the most commonly employed instrument [12, 30, 43–60]. This is not surprising considering that it is one of the most popular generic quality of life scales and has well-established psychometric properties across various populations [8, 69, 70]. The SF36 was designed as a measure of health status among adults irrespective of disease state [71, 72]. It consists of 36 items, which are grouped into the domains of physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health [72, 73]. Items within the subscales are summed up to provide a total score for each subscale, which is transformed into a linear scale of 0 (negative health) to 100 (positive health) [72, 73]. The popularity of the instrument coupled with its established psychometrics is likely to make the scale attractive to users who are seeking a popular, valid, and reliable instrument. However, despite evidence of good psychometrics, proper consideration to the contents of the instrument is paramount to selection of an appropriate scale [74].

Moreover, the conceptual and psychometric evaluation reveals that all the questionnaires vary in terms of content and psychometric properties (see Tables 4 and 5). For example, the Satisfaction with Life Scale (SWLS) is a unidimensional instrument, consisting of five items that assess global satisfaction with life condition [75]. Additionally, the Quality of life Profile (QP) has the least reported psychometric properties. Only the content validity of the instrument was reported by a single study, which found the items of the questionnaire relevant to polio survivors [13]. We could not find any other information about the psychometrics of the instrument. Hence, there is a need to establish the reliability and validity of the questionnaire. Most of the instruments have adequately reported properties, especially the SF36, NHP, QLI, WHOQOL-BREF, and EQD5. These findings are consistent with the literature, although there are some variations in the evaluation criteria employed [8, 69, 70]. For example, Coons et al. [71] adopted the review criteria developed by the Scientific Advisory Committee of the Medical Outcomes Trust, while Haywood et al. [70] employed predetermined criteria described by Streiner et al. [76]. Although these protocols may seem a little different, they share more in common than variability [42, 77, 78]. Despite having good evidence of psychometrics, the instruments included in this review were mostly evaluated in populations other than polio survivors. This may pose uncertainty regarding whether the scales will replicate the same properties if tested in polio survivors since inherent variations are likely to be found between two or more different populations [31]. Thus, quality of life evaluation among polio survivors based on these instruments should be interpreted with caution. Moreover, not all the identified studies reported adequate properties of these instruments, for example, in one of the validation studies of NHP, the criterion validity, that is, the correlation between the NHP and the criterion instrument was 0.39 [76]. This is below the minimum correlation of 0.50 recommended in the COSMIN checklist [42]. However, as psychometric evaluation of outcome measures is continuously being made, evidence establishing reliability and validity of these instruments in polio survivors is likely underway.

In summary, this review may serve purposes other than guiding the selection of an appropriate quality of life scale for polio survivors. It can be used to identify aspects of quality of life which are essential to polio survivors but are rarely covered by pre-existing instruments. It may facilitate the development of new scale or modification of pre-existing ones to cover items which are essential to polio survivors. It can also be used to establish face validity of the instruments. Lastly, the findings of the psychometric evaluation could also be used to justify the need for re-evaluation of these properties in polio survivors.

Limitations

Despite our effort to identify the instruments that are presently used for evaluating quality of life among polio survivors, analyze their contents, and evaluate their psychometrics, this scoping review has the following limitations. First, we searched only databases which are relevant to the study. Second, we excluded literature reviews in order to generate a manageable set of data. Thus, it is likely we might have missed relevant information from the literature reviews and other databases not included in our primary search. Moreover, we included studies that are published in English and we did not evaluate the quality of the studies that reported the psychometrics of the included instruments. These could result in missing other relevant studies and a combination of various degrees of evidence of psychometric properties.

Conclusion and recommendations

Quality of life scales are typically employed in cross-sectional and experimental studies among polio survivors. Findings of this scoping review show that the SF36, NHP, QLI, and EQD5 are the commonly used instruments for evaluating quality of life among polio survivors. Moreover, most of the instruments are self-reported and multidimensional. However, because the instruments are generic, there may be a lack of inputs of polio survivors in their development. This underscores the need for further qualitative validation of the relevance of the contents of these scales to polio survivors. In addition, most of these instruments have well-established psychometric properties, however, these properties are primarily reported from other populations. Thus, there is a need to re-evaluate the psychometrics of these instruments in polio survivors.

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