

RESEARCH ARTICLE

The cross-cultural validation of the Beach Center Family Quality of Life Scale among persons affected by leprosy or podoconiosis in Northwest Ethiopia

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Abstract

Background

The Beach Center Family Quality of Life Scale has been developed and validated in different languages in different countries. However, this scale has not been validated in the Ethiopian Amharic language context. Therefore, this study aimed to investigate the cross-cultural validity of the Beach Center Family Quality of Life Scale, among Ethiopian families of persons affected by leprosy and podoconiosis.

Methodology

We explored the semantic equivalence, internal consistency, reproducibility, floor and ceiling effects, and interpretability of the Beach Center Family Quality of Life Scale in Amharic. A cross-sectional study was conducted after the translation and back-translation of the instrument. A total of 302 adult persons affected by leprosy or podoconiosis was asked about their level of satisfaction with their family life, using the Beach Center Family Quality of Life Scale. In addition, 50 participants were re-interviewed two weeks after the initial assessment to test the reproducibility of the scale. Participants were recruited in the East Gojjam zone of Northwest Ethiopia.

Results

The findings of this study showed that the Beach Center Family Quality of Life Scale had high internal consistency (Cronbach's alpha of 0.913) and reproducibility (intra-class correlation coefficient of 0.857). The standard error of measurement was 3.01, which is 2.4% of the total score range. The smallest detectable change was 8.34. Confirmatory factor analysis showed adequate factor loadings and model fit indices like the original scale. The composite reliability and average variance extracted from the scale were acceptable. No floor and ceiling effects were found.

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Conclusions

Our findings indicate that the Amharic version of the Beach Center Family Quality of Life Scale has adequate cultural validity to assess the family quality of life in Ethiopian families of persons affected by leprosy and podoconiosis.

Author summary

The presence of persons with disabilities in the family can affect a family's quality of life. Neglected tropical diseases such as leprosy and podoconiosis can lead to disabilities and have been shown to affect family quality of life. We have selected the Beach Center Family Quality of Life scale to assess the family quality of life of persons affected by leprosy and podoconiosis. However, this scale has not been validated in the Ethiopian context previously. In this study, the authors aimed to investigate the cross-cultural validity of the Beach Center Family Quality of Life scale in families with one or more persons affected by leprosy or podoconiosis in Ethiopia.

A total of 302 participants were included in this study. The results show that the scale is adequately reliable and valid in the culture and language of the target country. Based on the findings, the authors recommend the use of this scale among families of persons affected by leprosy or podoconiosis.

Introduction

Family Quality of Life (FQoL) is an extension of individual quality of life (QoL) [1,2]. Recently, the concept of FqoL has developed out of the broader quality of life work and has been applied to families in which a member has an intellectual disability [3], and in families with members with other conditions such as Alzheimer's disease, serious medical conditions, and families living in disadvantaged communities [4]. FqoL is a multidimensional construct [2,5,6] and is defined as "conditions where the family's needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them" [7]. Using empirical data from their own literature review, Zuna et al. proposed four main concepts that influence variation in FQoL: (i) systemic concepts (systems, policies, and programs); (ii) performance concepts (services, supports, and practices); (iii) individual member concepts (demographics, characteristics, and beliefs); and (iv) family-unit concepts (characteristics, and dynamics) [2].

Interventions aimed at improving individual quality of life are more effective if we also take into account the family, cultural and environmental context [3,8–11]. FQoL is therefore one of the main outcome measures of services and the provision of family support for people with intellectual disabilities [6,8,12]. Guidance from family members is helpful for individuals with disabilities [13–16]. In this sense, in the past two decades, the FQoL concept has received more attention for its development and utilization [8,17], especially in the field of disability studies [18,19].

FQoL has been assessed using qualitative [5,8] and quantitative [9–11] approaches. Especially for the latter approach, scholars have developed different scales to measure FQoL, such as the Beach Center Family Quality of Life Scale (BC-FQoL) [10], the International Family Quality of Life scale [11], and a Latin America FQoL Scale [9]. Among these, we selected the BC-FQoL Scale [10] to measure the FQoL for families of persons with leprosy and

podoconiosis-related disabilities. Because this scale is one of the most widely used instruments to assess FQoL in families with special needs. It provides concise and quick information about families' overall well-being and can be used to address the needs of families caring for persons with disabilities in their homes [15]. In addition, the BC-FQoL is a psychometrically comprehensive measure that can be used in research and clinical practice to evaluate programs and services for families of children with disabilities [20].

The BC-FQoL scale was originally developed in the United States of America [10]. However, a scale developed in one country may not work in the same way in another country [21]. Based on this concept, a culturally adaptable, valid, and reliable scale plays a pivotal role in the measurement of FQoL of persons with disabilities and their family members. Previously, the BC-FQoL Scale has been validated in Spanish [6,8], Chinese [22,23], Turkish [24], and (Brazilian) Portuguese [25]. The BC-FQoL Scale has not been cross-culturally validated in the Ethiopian context. Therefore, the scale needs to be culturally validated in Ethiopia before it can be used to measure the FQoL persons affected by leprosy or podoconiosis.

Therefore, the aim of this study was to investigate the cross-cultural validity of the BC-FQoL scale among persons affected by leprosy and persons affected by podoconiosis in Northwest Ethiopia. Furthermore, we also aimed to conduct a cross-cultural adaptation of the BC-FQoL Scale to the Amharic language.

Methodology

Ethics statement

This study was approved by the Debre Markos University, Health Sciences College, Institutional Research Ethics Review Committee (IRERC) with reference number HSR/R/C/Se/Co/11/13. In addition, a permission letter was obtained from the Amhara Public Health Institute. The nature and objective of the study and the confidentiality of the data were clarified to each study participant before the data collection. Participation in the study was voluntarily. Because of the low level of literacy among the study participants, they gave verbal informed consent.

Study design

The study was a cross-sectional scale validation study.

Study site

This study was conducted in Northwest Ethiopia in the East Gojjam Zone. East Gojjam, also called Misraq Gojjam, is a zone in the [Amhara Region](#) of [Ethiopia](#). The zone's capital city is [Debre Markos](#). Debre Markos is located 300 km away from Addis Ababa, Ethiopia. It is bordered in the South by the Oromia Region, the West-by-West Gojjam, in the North by South Gondar, and in the East by South Wollo. The east Gojjam zone has a total population of 2,719,118 people, which comprise of 632,353 households. The zone also has 21 woredas (districts), 480 kebeles (the smallest administrative unit), 423 health posts, 102 health centers, 10 primary hospitals, and one referral hospital [26]. The main language is Amharic. Both leprosy and podoconiosis are prevalent in the area [27].

Study population, sample size and sampling technique

For the validation of the BC-FqoL, different population groups were selected for data collection. Out of the research team members, six experts participated in the translation, back translation, and evaluation process. Six persons with podoconiosis also participated for checking the completeness, understandability of the scale as part of the validation of the study. To

ensure quantitative validation, we sought to include 300 persons affected by leprosy or podocniosis with disabilities who are adults and have a view of their family life. Different scholars recommended different ways of calculating the sample size. Based on Terwee et al. 7 person for 1 item of the scale [28], Kline recommends a participant to indicator ratio of 10 up to 20:1 [29], and Viswesvaran 15 persons for 1 item or 30 persons for 1 item [30]. However, according to Comfrey and his colleagues, a sample size of 50 is considered very poor, 100 is considered poor, 200 is considered fair, 300 is considered good, 500 is considered very good, and 1000 or more as excellent [31]. Based on their recommendations, we opted to use a sample size of 300 on the basis that it would be sufficiently accurate for our needs. Participants were selected based on convenience sampling. In addition, 50 samples were randomly selected from the initial sample. These people were re-interviewed two weeks after the original interviews check the consistency of the scale used.

Eligibility criteria

For the translation, evaluation, and back translation of the BC-FQoL Scale we involved researchers, language experts, psychologists, mental health experts and one of the original scale developers. For the quantitative validation, participants who had to live in one of the five districts were included in the study. The persons affected by leprosy had to be diagnosed and treated before the time of the interview, and have visible impairment due to their condition. Persons unwilling or unable to give verbal informed consent, under 16 years and over 80 years of age were excluded.

Measures

The BC-FQoL scale was originally developed by researchers at the Beach Center on Disability, a research and training center of the University of Kansas [10]. The scale is intended to quantify the insights and levels of satisfaction persons with disabilities experience within their family quality of life [7]. This scale contains 25 items with a 5-point Likert scale (1- very dissatisfied, 2- dissatisfied, 3- neither satisfied nor dissatisfied, 4- satisfied, and 5- very satisfied). The scale consists of five subscales: 1) family interaction (6 items), 2) parenting (6 items), 3) emotional well-being (4 items), 4) physical/material well-being (5 items) and 5) disability-related support (4 items). The total scores for the satisfaction ratings range from 25 to 125 [10]. In addition to the scale, socio-demographic information was also collected.

Translation and adaptation process

We adapted the original English version of the BC-FQoL to Amharic using the procedure outlined by Borsa et al. [32]. The cross-cultural validation of the BC-FQoL measurement scale consisted of two main phases. The first phase entailed translation and adaptation, which itself has five stages: 1) instrument translation from the source language (English) into the target language (Amharic), 2) synthesis of the translated content, 3) a synthesis evaluation by experts, 4) tool evaluation by the target population (persons with leprosy and podocniosis), and 5) back translation into the English language. In addition, different equivalence of the scale and its subscales was assessed based on different definitions and criteria such as the conceptual equivalence pursued through a rigorous process, including forward and backward translation. Item equivalence is considered the degree to which the items composing the instrument are identical across cultures. Operational equivalence refers to the possibilities of using a similar questionnaire format, instructions, mode of administration and measurement methods [28]. The second phase entailed a quantitative validation (assessment of measurement equivalence).

For the initial step of the first phase, the English version of the BC-FQoL Scale was translated by two authors whose mother tongue is Amharic. First, the researchers performed the

translation independently and then the two translated versions were compared and discussed to ensure semantic equivalence and agreement with the conceptual framework of the original scale. In cases of disagreement between the two authors, a third person was invited to solve the disagreement. This was facilitated using three additional experts (a psychologist, an Amharic language professor, and a psychiatrist) whose mother tongue is also Amharic. Moreover, the three experts were also invited to assess the translation's semantic equivalence and provide the authors with written feedback.

Back-translation to English was performed by two professors who were fluent in English and Amharic. The back-translation was also done independently and without disclosing the original version of the scale to the translators. The back-translated version was compared to the original scale by three authors, and small changes were consequently made on the back translated version of the scale. Finally, the translated and back-translated scale was sent to the original scale developers who were asked to review the translations. Based on their feedback, minor corrections were made to the Amharic version of the scale.

Furthermore, six persons affected by podoconiosis were asked to assess the legibility, clarity, and cultural suitability of the Amharic version of the scale. These persons reported that the items reflected their ideas, and the wording of the items was clear and could be easily understood. The scale demonstrated adequate face validity. It took about 25 minutes per participant to complete the interviews with each of the six persons affected by podoconiosis.

Data collection

Seven health professionals participated in the data collection process. A two-day training on the objective of the study and the details of the scale was given to them by two authors of this article. The data collectors contacted persons with leprosy and podoconiosis in their homes, and around their locality. This was done after contacting them through their kebele (a small administrative unit) and leprosy association leaders. The data collectors explained the objectives of the study and obtained verbal informed consent before the start of the interview. Confidentiality of the data was guaranteed throughout the study. Participants were interviewed face to face at their homes or around their locality in a quiet room. The data were collected from August–October 2021.

Data analysis

Epi data version 3.1 was used for data entry and SPSS version 25.0 for data analysis. SPSS AMOS version 21.0 was used for confirmatory factor analysis (CFA).

Different statistical analyses were carried out to determine the reliability of the Beach Center FQoL scale as translated into Amharic. Cronbach's alpha was calculated for the total score of the scale and the subscales to determine the internal consistency of the instrument. In addition, the test–retest procedure was used to evaluate the reliability and reproducibility of measures. This was done with a subsample comprising 50 participants from the overall sample and using a time interval of two weeks. The test-retest reliability was assessed using the intra-class correlation coefficient (ICC) and its corresponding 95% confidence interval. The internal consistency and test-retest reliability were considered acceptable when the values of Cronbach's alpha and ICC exceeded 0.70 [33,34]. The standard error of measurement (SEM_{agreement}) was also calculated to determine the reproducibility of the scale, using the formula $SEM = SD \cdot \sqrt{1-ICC}$. The SEM was also converted into the smallest detectable change ($SDC = 1.96 \times \sqrt{2} \times SEM$), which reflects the smallest within-person change in score. With a $P < 0.05$, this can be interpreted as a “real” change, above measurement error, in one individual (SDC_{ind}). The SDC is measurable in a group of people (SDC_{group}) can be calculated by dividing the SDC_{ind}

by \sqrt{n} . Values above the SDC describe a change in the individual's score above the error of the measurement [35,36].

Floor and ceiling effects were also calculated. Floor and ceiling effects are considered present if more than 15% of the respondents achieved the lowest or highest possible score on the scale [36–38].

Finally, Confirmatory Factor Analysis (CFA) with the maximum likelihood estimation was performed to examine the dimensionality and construct validity of the five-factor structure of the BC-FQoL. When the first-order latent variables were mutually related and can be accounted by a second-order latent variable. We examined whether the second-order five-factor structure of the BC-FQoL fits the Ethiopian family context of persons affected by leprosy and podoconiosis. Model fit was assessed using fit indices including the ratio of χ^2 to the degrees of freedom (the χ^2/df ratio), the goodness-of-fit index (GFI), the adjusted goodness-of-fit index (AGFI), the root means square error of approximation (RMSEA), the comparative fit index (CFI) and the incremental fit index (IFI). A value of 0.90 or more for the CFI and IFI [39], a value of less than 5 for χ^2/df , a value of 0.80 or more for the GFI and AGFI, and an RMSEA value between 0.05 and 0.08 are considered good model fit [40]. In addition, construct reliability (composite reliability (CR)) of 0.70 or more, and average variance extracted (AVE) of 0.50 or more were used to assess the convergent validity [41].

Results

Semantic equivalence

Minor changes were made to the first version of the back-translated English version of the scale. For example, for item number 2, originally said, “My family members help the children learn to be independent.” Interpreter 1, translated this as “My family members support children to be self-dependent and responsible.” Interpreter 2 translated this as “My family members help children to know about self-reliance/management.” We have selected interpreter 2's translation by avoiding “management” at the end of the translated statement. Similarly for item number 13, “My family has outside help available to us to take care of special needs of all family members.” Interpreter 1 translated this as “There is another body/person to support my family in times of difficulty.” Interpreter 2 translated it as “We have another person or person to take care of the special needs of my family members.” Based on this we have selected the later translation.

Socio-demographic characteristics of the study participants

A total of 302 persons affected by leprosy ($n = 166$, 55%) and podoconiosis ($n = 136$, 45%) participated in the study. Over half of the study participants were male ($n = 178$, 59%), and three quarters of the study participants ($n = 226$, 75%) were below 64 years of age (18–64 years, which is independent age segment of the population in Ethiopian context). The mean age of the study participants was 54 (± 14.2) years and a range of 18 to 80 years. About 79% ($n = 239$) of the study participants had a family size of below five people (which is the average family size of Ethiopia 4.8). Almost 80% ($n = 241$) of the participants were not able to read and write and most of the participants ($n = 265$, 88%), were farmers. An overview of the demographic information of the participants can be found in [Table 1](#). [Table 1](#) also includes the demographic characteristics of the 50 participants that were interviewed again after two weeks.

Internal consistency

The internal consistency of the BC- FQoL Scale, the overall Cronbach's alpha, was 0.913. For the five subscales, the Cronbach's alpha ranged from 0.683 to 0.850. In addition, different

Table 1. Sociodemographic characteristics of persons affected by leprosy and podoconiosis.

Variables		First assessment (n = 302)		Follow-up assessment (n = 50)	
		N	(%)	N	(%)
Sex	Male	178	59	32	64
	Female	124	41	18	36
Age (years)	≤64	226	75	39	78
	>64	76	25	11	22
Family size	≤5	239	79	33	66
	>5	63	21	17	34
Educational status	Can't read and write	241	80	29	58
	Can read and write	38	13	16	32
	Elementary school	13	4	2	4
	High school and above	10	3	3	6
Occupation	Farmer	265	88	42	84
	Merchant	13	4	1	2
	Other*	24	8	7	14
Condition	Leprosy	166	55	26	52
	Podoconiosis	136	45	24	48

*Waiver (n = 3), daily laborer (n = 5), guard (n = 3), carpenter (n = 2), housewife (n = 4), student (n = 2), employee (n = 1) and unemployed (n = 4).

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items were deleted, and Cronbach's alpha was calculated. However, there was no visible difference in the Cronbach alpha of both the subscales and the overall BC-FQoL Scale. Reliability statistics are summarized in [Table 2](#).

Reproducibility: reliability and agreement

The BC-FQoL scale total score ICCagreement was 0.857 (95% CI: 0.761–0.916, $p < 0.001$). For the five subscales, the ICCagreement ranged from 0.508–0.847. The subscale ICCagreement is summarized in [Table 2](#). The standard error of measurement (SEM) was 3.01, which is 2.4% of

Table 2. Reliability of the translated BC-FQoL scale.

Subscales	No. of items	Cronbach's alpha (n = 302)	Cronbach's alpha (if item is deleted) (n = 302)	ICCagreement (95% CI) (n = 50)	SEM (n = 50)	SEM as % of total score range	SDC _{ind} = SDC (n = 50)	SDC _{group} (n = 50)
Family interaction	6	0.779	0.803 (N18)	0.613(0.404, 0.760) *	2.35	7.8%	6.51	0.92
Parenting	6	0.692	0.697 (N17)	0.578(0.362, 0.736) *	2.56	8.5%	7.10	1.00
Emotional well-being	4	0.683	0.708 (N9)	0.508(0.268, 0.688) *	1.57	7.9%	4.35	0.62
Physical/material well-being	5	0.728	0.718 (N21)	0.618(0.411, 0.764) *	1.95	7.8%	5.41	0.76
Disability-related support	4	0.850	0.842 (N24)	0.847(0.744, 0.910) *	0.92	4.6%	2.55	0.36
FQoL total score	25	0.913	0.913 (FI)	0.857(0.761,0.916) *	3.01	2.4%	8.34	1.18

* $P < 0.001$, N represent item number of the BC-FQoL Scale

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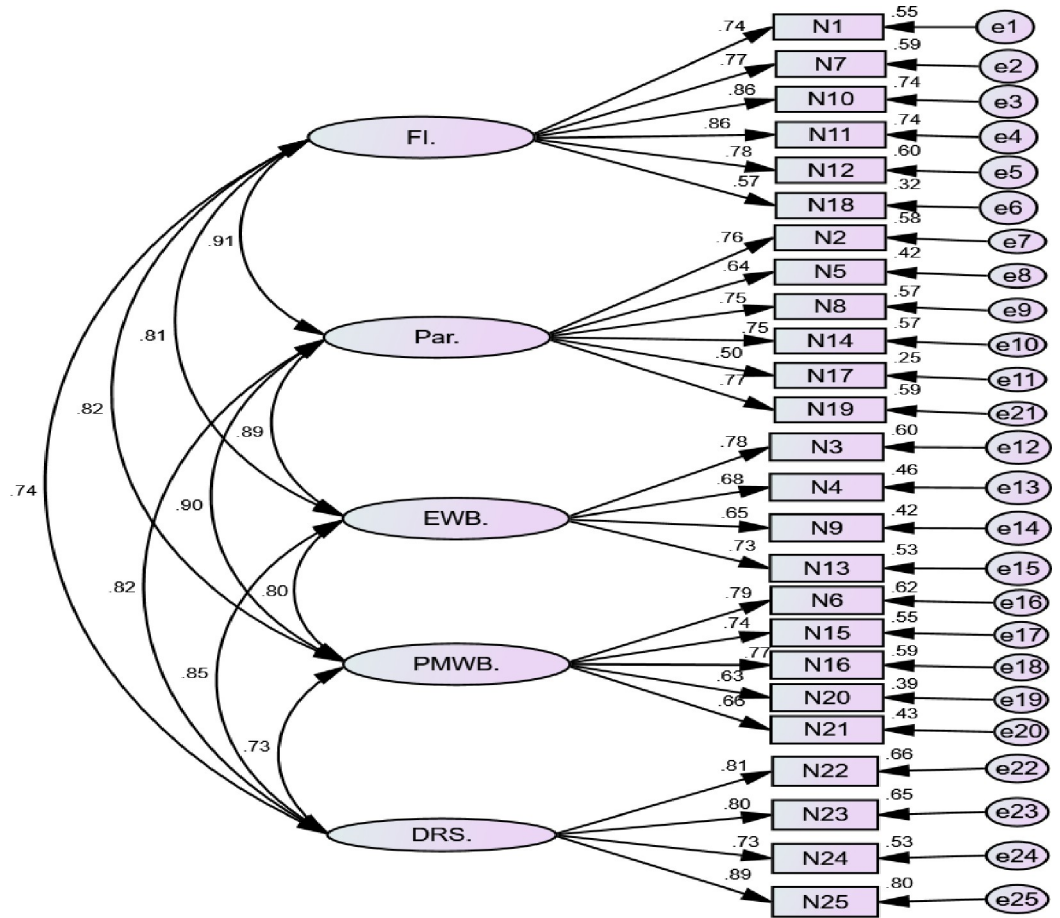


Fig 1. Measurement model of the Beach Center Family Quality of Life scale and its result. FI.—Family interaction, Par.—Parenting, EWB.—Emotional-wellbeing, PMWB.—Physical/ Material Wellbeing, DRS.—Disability-related support.

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the total score range. The smallest detectable change (SDC) was 8.34, and the SDC group 1.18. Details are summarized in Table 2.

Validity

The five-factor CFA model yielded an acceptable model fit and the five first-order latent variables correlated well with each other, 0.73–0.91; all $p < 0.001$ (Fig 1). Therefore, we conducted a second-order CFA model to examine the validity of the BC-FQoL (Fig 2). The standardized factor loadings were all significant ($p < 0.001$), ranging from 0.65 to 0.99 ratings. Items all loaded well on the expected latent constructs. The results suggested that improving the model fit indices yielded an almost adequate fit (the χ^2/df ratio 2.941; GFI .820; AGFI .791; IFI .818; CFI .817 and RMSEA 0.08). This result came after removing item number 5 from the parenting subscale, item number 9 from the emotional well-being subscale and item number 25 from disability-related support subscale. The CR values were all well above 0.70 for the satisfaction ratings. The AVE values which satisfied the criteria of 0.50 and above for all the subgroups of the BC-FQoL, except the parenting which was almost on the margin of 0.5 (0.492). Details can be found in Table 3.

Floor and ceiling effects

There are no floor and ceiling effects (Table 4).

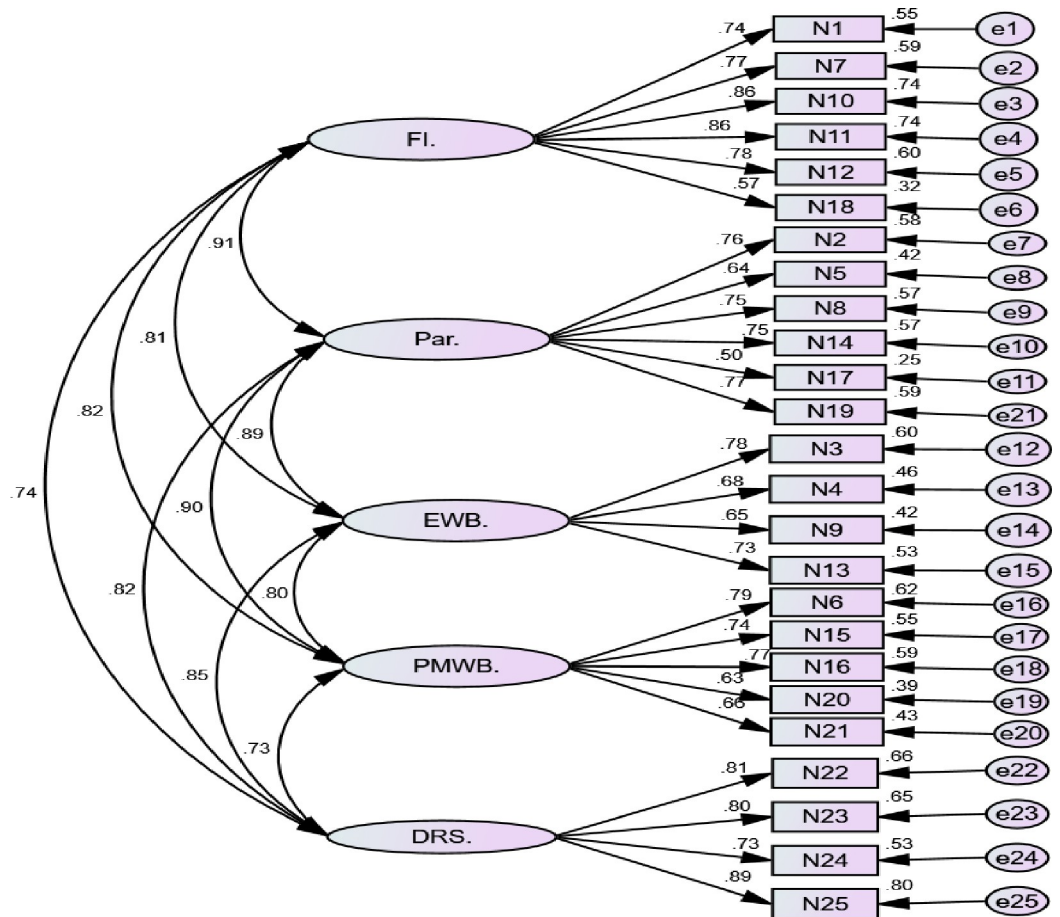


Fig 2. Standardized parameter estimates from confirmatory factor analysis of the Beach Center Family Quality of Life scale: second-order five-factor model. FQoL.—Family Quality of Life, FI.—Family interaction, Par.—Parenting, EWB.—Emotional-wellbeing, PMWB.—Physical/Material Wellbeing, DRS.—Disability-related support.

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Interpretability

The mean and SD of the different subgroups of the baseline data (n = 302) show varied results as illustrated in Table 4.

The mean total score of the BC-FQoL scale is higher in male participants. Among age groups, the BC-FQoL is slightly higher in the ≤64 years category. The BC-FQoL scale mean total scores were highest within the ‘able to read and write’ category, followed by the ‘can’t read and write’ category among education groups. From the occupation group ‘merchants’, the total mean score was higher than ‘farmers’ and other occupations. Finally, BC-FQoL total

Table 3. The subgroup of BC-FQoL composite reliability and average variance extracted.

	Composite reliability	Average Variance Extracted
Family interaction	0.896	0.592
Disability related support	0.884	0.658
Physical/material well-being	0.841	0.516
Emotional well-being	0.802	0.504
Parenting	0.852	0.494

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Table 4. Floor and ceiling effect of BC-FQoL scale among persons affected by leprosy and podoconiosis.

(Sub)scale	Range of (sub)scale	Number of people with the lowest score	Floor effect*	Number of people with the highest score	Ceiling effect*
Family interaction	6–30	1	No	15	No
Parenting	6–30	1	No	4	No
Emotional WB	4–20	11	No	4	No
Physical WB	5–25	3	No	3	No
Disability-related support	4–20	6	No	26	No
FQoL total score	25–125	0	No	0	No

*) The total number of participants is 302. This means floor and ceiling effects are present, when 45 people (15%) have the lowest or highest possible score.

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scores are higher among persons affected by leprosy in comparison to persons with podoconiosis. Details of this are presented in [Table 5](#).

Discussion

This study aimed to validate the BC-FQoL Scale cross-culturally into the Amharic language, and subsequently report the cross-cultural validation and psychometric properties of the scale in persons with leprosy or podoconiosis in Northwest Ethiopia.

The cross-cultural adaptation and validation of the BC-FQoL Scale was performed based on the recommendations of different scholars [28, 32] review. Semantic equivalence was assessed through a process of translation and back-translation. Following these steps, small corrections were made to the Amharic translation of the BC-FQoL scale. This was done based on expert evaluations and the feedback of the original tool developers and input of the target population.

The quantitative data analysis results of this study showed a high level of reliability or internal consistency, higher than the cut-off value of 0.7 for Cronbach's alpha [34, 42]. It was also

Table 5. The mean and standard deviation of Beach Center Family Quality of Life Scale among persons affected by leprosy and podoconiosis.

Variables	Mean (SD)	
Sex	Male (n = 178)	77.09(17.50)
	Female (n = 124)	73.19(17.65)
Age (Years)	≤64 (n = 226)	74.72(18.60)
	>64 (n = 76)	73.29(21.13)
Family size	≤5 (n = 239)	74.72(18.59)
	>5 (n = 63)	78.41(13.14)
Educational status	Can't read and write (n = 241)	75.07(17.40)
	Can read and write (n = 38)	82.42(24.39)
	Elementary school (n = 13)	68.77(24.35)
	High school and above (n = 10)	68.10(20.51)
Occupation	Farmer (n = 265)	75.89(16.56)
	Merchant (n = 13)	86.46(24.39)
	Other* (n = 24)	65.17(20.71)
Type of diseases affected person	Leprosy (n = 166)	76.93(13.51)
	Podoconiosis (n = 136)	73.73(21.55)

*Waiver (n = 3), daily laborer (n = 5), guard (n = 3), carpenter (n = 2), housewife (n = 4), student (n = 2), employee (n = 1) and unemployed (n = 4).

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consistent with the original scale and other researchers' findings of internal consistency of the BC -FQoL [10, 23, 43]. The Cronbach's alpha of the subgroups was also in the acceptable range in all cases except for the parenting and emotional well-being subgroups, which was nearer to 0.7. Similarly, the result showed an overall excellent agreement or substantial reliability of test-retest ICC of the scale in comparison to different validation studies [34, 35]. This is comparable with a validation study on the Spanish adaptation and validation of the BC -FQoL Scale [43].

The standard error of measurement of the BC-FQoL Scale was <5%, which is considered a very good SEM agreement and is within the acceptable range. This is because of the percentage of the standard error of measurement (SEM) related to the total score of the questionnaire [42, 44]. The SDC of the BC-FQoL Scale was also within an acceptable range, which is in line with findings from other researchers [35, 45–47].

Our CFA indicated that the Amharic version of the BC-FQoL Scale produces reliable results. The first and second-order CFA models showed an acceptable factor loading for all items except item 17 (0.47) which has the nearest margin of 0.5. Overall, this result is comparable with the study done by Chiu et al. in China [23], Verdugo et al. in Spain [43] and the original BC-FQoL scale [10]. Similarly, the model fit indices were within acceptable range even though these results came after improving the model by removing items 5, 9 and 25 from the Scale. However, the items which were removed were considered necessary by the experts in the present study, as each item addresses important points in their respective subgroups. For example, item 5 in parenting, which is "my family members help the children with schoolwork and activities", is vital because of the effect of disability on education [48]. Item 9, "my family members have some time to pursue our own interests", was also considered essential in the Ethiopian context, which considers giving time to other members of the family an asset of Ethiopian family culture. In addition, item 25, "my family has good relationships with the service providers who provide services and support to our family member with a disability", has great importance within the Ethiopian context because of the stigma related to disability [48].

Thus the model fit indices results were comparable with the original validation study [10] and other validation studies of the BC-FQoL scale [8, 43]. This study found high composite reliability (CR) which indicated how the subgroup items showed composite reliability to each other within the BC-FQoL scale. This is similar to the study findings with the original scale [10] and Mandarin Chinese versions of the scale results [23].

The convergent validity of this study result indicated an acceptable range even though the average variance extracted (AVE) of the parenting subgroup was 0.494, close to the cut-off value of 0.5. However, this is acceptable on the basis of research done by Fornell and Larcker, which states that if AVE is less than 0.5, and CR is higher than 0.6, the convergent validity of the construct is still tolerable [49]. This was also the case in our study.

Besides the above measure of reliability and validity of the BC-FQoL Scale, there were no floor and ceiling effects overall and the subgroups. These have good implications for the reproducibility and responsiveness of the scale [28, 38].

In this validation study, the mean total score of the BC-FQoL scale is higher in male participants. This is supported by the study conducted in Ethiopia [50]. Because females engaged more in caregiver stress and not taking on major social roles in education and employment [51]. In addition, Tsutsumi et al. study result showed an overall lower quality of life score for women than men, a higher mental burden among women compared to men, and perceived stigma affecting QoL of women more negatively than that of men [52]. The BC-FQoL is slightly higher in the ≤ 64 years category. Because those above 64 years of age are a dependent group of the family in the Ethiopian context [53]. Moreover, the BC-FQoL Scale mean total scores were highest within the 'able to read and write' category. This result supported adults with disabilities tend to be poorer than those without disabilities, but education weakens this

association [54]. Finally, BC-FQoL total scores are higher among persons affected by leprosy in comparison to persons with podoconiosis. This finding is supported by the study done in Ethiopia [50] persons affected by podoconiosis are more stigmatized and discriminate against than persons affected by leprosy. Persons affected by leprosy were association members that gave a chance of getting support from their peers and this provides a sense of empowerment [55]. On the other hand, association members of associations of persons affected by leprosy have a chance to take a loan from the association. This is supported by research conducted by Wang et al, which indicated that family income is associated with family quality of life [56].

One of the limitations of this study was the use of a convenience sampling technique. We have asked those persons affected by leprosy or podoconiosis who have a view of the family but have not addressed the family members in this study. Use of the instrument in a more heterogeneous and representative sample of families with disabilities receiving disability management intervention may be needed to further validate the scale. Other studies on the use of the Amharic version of the BC-FQoL are needed in other Amharic-speaking populations and in families of disabled children or families of adults without disabilities, to support its use in other populations. The study used a cross-sectional design to validate the BC-FQoL.

Conclusion and Recommendation

The Amharic version of the BC -FQoL is reliable and valid in families of persons affected by leprosy and podoconiosis in Northwest Ethiopia. The instrument could be applied in clinical practice, service evaluation and research to assess FQoL in Amharic-speaking populations with leprosy and podoconiosis-related disabilities which were or are the recipients of family-based disability management intervention.

Supporting information

S1 STROBE. Checklist of FQoL Scale.

(DOCX)

S1 Table. FQoL Scale developer feedback.

(DOCX)

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References

1. Turnbull AP, Turnbull HJRPIISE. From the old to the new paradigm of disability and families: Research to enhance family quality of life outcomes. 2002;83–119.
2. Zuna NI, Turnbull A, Summers JA. Family quality of life: Moving from measurement to application. *Journal of Policy Practice in Intellectual Disabilities*. 2009; 6(1):25–31.
3. Summers JA, Poston D, Turnbull A, Marquis J, Hoffman L, Mannan H, et al. Conceptualizing and measuring family quality of life. 2005; 49(10):777–83. <https://doi.org/10.1111/j.1365-2788.2005.00751.x> PMID: 16162127
4. Zuna NI, Brown I, Brown RI. Family quality of life in intellectual and developmental disabilities: A support-based framework to enhance quality of life in other families. 2014.
5. Poston D, Turnbull A, Park J, Mannan H, Marquis J, Wang M. Family quality of life: A qualitative inquiry. *J Mental retardation*. 2003; 41(5):313–28. [https://doi.org/10.1352/0047-6765\(2003\)41<313:FQOLAQ>2.0.CO;2](https://doi.org/10.1352/0047-6765(2003)41<313:FQOLAQ>2.0.CO;2) PMID: 12962536
6. Schalock RL, Verdugo MA, Braddock DL. *Handbook on quality of life for human service practitioners*: American Association on Mental Retardation Washington, DC; 2002.
7. Park J, Hoffman L, Marquis J, Turnbull AP, Poston D, Mannan H, et al. Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *J Journal of intellectual disability research*. 2003; 47(4–5):367–84. <https://doi.org/10.1046/j.1365-2788.2003.00497.x> PMID: 12787167
8. Balcells-Balcells A, Giné C, Guàrdia-Olmos J, Summers JJOIDR. Family quality of life: Adaptation to Spanish population of several family support questionnaires. 2011; 55(12):1151–63.
9. Aznar A, Castanon DJJOIDR. Quality of life from the point of view of Latin American families: A participative research study. 2005; 49(10):784–8.
10. Hoffman L, Marquis J, Poston D, Summers JA, Turnbull AJJOM, Family. Assessing family outcomes: Psychometric evaluation of the beach center family quality of life scale. 2006; 68(4):1069–83.
11. Isaacs BJ, Brown I, Brown RI, Baum N, Myerscough T, Neikrug S, et al. The international family quality of life project: Goals and description of a survey tool. 2007; 4(3):177–85.
12. Turnbull AP, Summers JA, Lee SH, Kyzar KJMR, Reviews DDR. Conceptualization and measurement of family outcomes associated with families of individuals with intellectual disabilities. 2007; 13(4):346–56.
13. Lindstrom L, Doren B, Miesch JJEC. Waging a living: Career development and long-term employment outcomes for young adults with disabilities. 2011; 77(4):423–34.
14. Rupp K, Ressler SJJQVR. Family caregiving and employment among parents of children with disabilities on SSI. 2009; 30(3):153–75.

15. Samuel P, Rillotta F, Brown IJJOIDR. The development of family quality of life concepts and measures. 2012; 56(1):1–16.
16. Fong VC, Gardiner E, Iarocci GJA. Cross-cultural perspectives on the meaning of family quality of life: Comparing Korean immigrant families and Canadian families of children with autism spectrum disorder. 2021; 25(5):1335–48.
17. McWilliam R. Working with families of young children with special needs: Guilford Press; 2010.
18. Wang M, Kober RJJOIDR. Embracing an era of rising family quality of life research. Wiley Online Library; 2011. p. 1093–7.
19. Hsiao YJJJOP, Disabilities PII. Autism spectrum disorders: Family demographics, parental stress, and family quality of life. 2018; 15(1):70–9.
20. Van Beurden AJRA. Critical evaluation of the Beach Center Family Quality of Life Scale (FQOL-Scale). 2011; 26(2016):2010–11.
21. Hirsh-Pasek K, Kochanoff A, Newcombe NS, De Villiers JJSFRICD. Using Scientific Knowledge to Inform Preschool Assessment: Making the Case for "Empirical Validity". Social Policy Report. Volume 19, Number 1. 2005.
22. Hu X, Wang M, Fei XJJOIDR. Family quality of life of Chinese families of children with intellectual disabilities. 2012; 56(1):30–44.
23. Chiu SJ, Chen PT, Chou YT, Chien LYJJOIDR. The Mandarin Chinese version of the Beach Centre Family Quality of Life Scale: development and psychometric properties in Taiwanese families of children with developmental delay. 2017; 61(4):373–84.
24. Meral BFJEVB. Turkish adaptation, validity and reliability study of the Beach Center Family quality of life scale. 2013; 38(170).
25. Jorge BM, Levy CCaDC, Granato L, editors. Cultural adaptation quality of family life scale for the Brazilian Portuguese. CoDAS; 2015: SciELO Brasil.
26. Department EGZH. Six Month Report. 2022.
27. Molla YB, Tomczyk S, Amberbir T, Tamiru A, Davey GJPNTD. Podoconiosis in East and west gojam zones, northern ethiopia. 2012; 6(7):e1744.
28. Terwee CB, Bot SD, De Boer MR, Van Der Windt DA, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. 2007; 60(1):34–42. <https://doi.org/10.1016/j.jclinepi.2006.03.012> PMID: 17161752
29. Kline RB. Principles and practice of structural equation modeling: Guilford publications; 2015.
30. Viswesvaran CJPP. Multiple regression in behavioral research: Explanation and prediction. 1998; 51(1):223.
31. Comrey A, Lee HJL, Publishers. A first course in factor analysis. Hillsdale, NJ, Lawrence Erlbaum Associates. 1992.
32. Borsa JC, Damásio BF, Bandeira DRJP. Adaptación y validación de instrumentos psicológicos entre culturas: Algunas consideraciones. 2012; 22(53):423–32.
33. Henson RKJM, Counseling EI, Development. Understanding internal consistency reliability estimates: A conceptual primer on coefficient alpha. 2001; 34(3):177–89.
34. Hartley SL, Maclean WJJOIDR Jr. A review of the reliability and validity of Likert-type scales for people with intellectual disability. 2006; 50(11):813–27.
35. Darter BJ, Rodriguez KM, Wilken JMJRQFE, Sport. Test–retest reliability and minimum detectable change using the k4b2: oxygen consumption, gait efficiency, and heart rate for healthy adults during submaximal walking. 2013; 84(2):223–31.
36. Costa LDCM Maher CG, Mcauley JH Hancock MJ, De Melo Oliveira W, Azevedo DC, et al. The Brazilian-Portuguese versions of the McGill Pain Questionnaire were reproducible, valid, and responsive in patients with musculoskeletal pain. 2011; 64(8):903–12.
37. Davidson G, Irvine R, Corman M, Kee F, Kelly B, Leavey G, et al. Measuring the quality of life of people with disabilities and their families: scoping study final report. 2017.
38. Maher CG, Latimer J, Costa LOJBJOPT. The relevance of cross-cultural adaptation and clinimetrics for physical therapy instruments. 2007; 11:245–52.
39. Abd-El-Fattah SMJJOaQM. Structural Equation Modeling with AMOS: Basic Concepts, Applications and Programming. 2010; 5(2):365–8.
40. Hair JF, Anderson RE, Babin BJ, Black WC. Multivariate data analysis: A global perspective (Vol. 7). Upper Saddle River, NJ: Pearson; 2010.
41. Hair Junior JF, Hult GTM, Ringle CM, Sarstedt M. A primer on partial least squares structural equation modeling (PLS-SEM). Los Angeles: Sage; 2014.

42. Oliveira IS, Costa L, Manzoni AC, Cabral CJBJOPT. Assessment of the measurement properties of quality of life questionnaires in Brazilian women with breast cancer. 2014; 18:372–83.
43. Verdugo M, Córdoba L, Gómez JJJOIDR. Spanish adaptation and validation of the Family Quality of Life Survey. 2005; 49(10):794–8.
44. Ostelo RW, De Vet HC, Knol DL, Van Den Brandt PaJJOCE. 24-item Roland-Morris Disability Questionnaire was preferred out of six functional status questionnaires for post-lumbar disc surgery. 2004; 57(3):268–76.
45. Brehm M-A, Nollet F, Harlaar JJaOPM, Rehabilitation. Energy demands of walking in persons with post-poliomyelitis syndrome: relationship with muscle strength and reproducibility. 2006; 87(1):136–40.
46. Mclaughlin JE, King G, Howley ET, Bassett DR Jr, Ainsworth BEJJOSM. Validation of the COSMED K4 b2 portable metabolic system. 2001; 22(04):280–4.
47. Geerinck A, Alekna V, Beaudart C, Bautmans I, Cooper C, De Souza Orlandi F, et al. Standard error of measurement and smallest detectable change of the SarQoL questionnaire: an analysis of subjects from 9 validation studies. 2019; 14(4).
48. Van 'T Noordende AT, Aycheh MW, Schippers AJPNTD. The impact of leprosy, podoconiosis and lymphatic filariasis on family quality of life: A qualitative study in Northwest Ethiopia. 2020; 14(3):e0008173.
49. Fornell C, Larcker DFJJOMR. Evaluating structural equation models with unobservable variables and measurement error. 1981; 18(1):39–50.
50. Van't Noordende AT, Aycheh MW, Schippers APJTOTRSOTM, Hygiene. An exploration of family quality of life in persons with leprosy-, lymphatic filariasis—and podoconiosis-related disabilities and their family members in Ethiopia. 2020; 114(12):1003–12.
51. Tefera B, Van Engen M, Van Der Klink J, Schippers AJD, Society. The grace of motherhood: disabled women contending with societal denial of intimacy, pregnancy, and motherhood in Ethiopia. 2017; 32(10):1510–33.
52. Tsutsumi A, Izutsu T, Islam MA, Amed JU, Nakahara S, Takagi F, et al. Depressive status of leprosy patients in Bangladesh: association with self-perception of stigma. 2004; 75(1):57–66.
53. Bank TW. Ethiopia: Age dependency ratio. 2021.
54. Filmer DJTWBER. Disability, poverty, and schooling in developing countries: results from 14 household surveys. 2008; 22(1):141–63.
55. Solomon PJPRJ. Peer support/peer provided services underlying processes, benefits, and critical ingredients. 2004; 27(4):392.
56. Wang M, Turnbull AP, Summers JA, Little TD, Poston DJ, Mannan H, et al. Severity of disability and income as predictors of parents' satisfaction with their family quality of life during early childhood years. 2004; 29(2):82–94.