Original Article

Development And Psychometric Properties Of A Quality Of Life Questionnaire For Siblings Of Children With Cancer: A Mixed-Method Study

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Abstract

Background: Family members of children with cancer experience stressful and unpredictable conditions in their lives. This condition can impact on family members’ roles, communications, and values and disrupt the family’s quality of life (QoL), especially the QoL of the healthy siblings of the sick child. The purpose of the study was to develop a QoL Questionnaire for siblings of children with cancer and to evaluate of its psychometric properties.

Methods: This is a mixed-method study with an exploratory sequential design. In the qualitative phase, the concept of QoL in siblings of children with cancer and its dimensions were explored by interviewing 17 adolescents, four mothers and four oncology nurses. Subsequently, the phase of integrative review for access to similar questionnaires was conducted. In the next phase, the results of integrating review and the qualitative phase was integrated. In the quantitative phase of the study, the face, content, and construct validity, reliability, and feasibility of the questionnaire were evaluated.

Results: From the qualitative phase, five themes were extracted. After integrating the results of two first phases, an item-scale pool with 145 items was created. Following exploratory factor analysis (EFA), 46 items remained in the questionnaire and six factors were extracted: “adaptation to condition”, “psycho-emotional functioning”, “individual functioning”, “illness burden on the family”, “daily life challenges” and “spiritual adjustment.”

Conclusions: The Iranian version of the QoL questionnaire for siblings of children with cancer was developed. It showed to be a valid and reliable questionnaire. It can measure the QoL of adolescent siblings of children with cancer in our context. It is suggested that in the future research, further development was done in various age groups of children, and in different societies.

Keywords: Cancer, Quality of life, Sibling, Psychometrics

INTRODUCTION

Cancers are among children’s chronic diseases that influence family members, especially healthy siblings (1). They can change roles and structure of the family(2). This leads to negative and positive effects (internalized and/or externalized problems, physical and/or psycho-social adaptation disorders) on siblings’ health in the present and/or in the future (3, 4). Siblings of sick children describe themselves as forgotten members of the family. Similar to the sick child, they may report a considerable number of changes in their daily functioning(5) and experience limitations in their familial and social life and delays in their growth and development (4). Childhood cancer and its treatment can significantly affect psycho-social adaptation of the sick child and their siblings (6). Therefore, quality of life (QoL) of the sick child and their families, especially adolescents are affected (7). Adolescence is the most sensitive and critical period in the transition between childhood and adulthood. Improved thinking ability, maturation, changes in relationships with family, friends, school and society, expectations of peers, family and society, family roles, responsibilities, and efforts to acquire new emotional and social roles for the future, are some of the crucial events of this period (8). Adolescence can be accompanied by several stressful situations, such as academic competition, familial conflicts, identification and romantic relationships (9)Evidence shows that personal, familial and social indicators and disease-related factors affect the QoL in siblings of children with chronic disease(10-12).

QoL is a concept which affected by the context and includes physical, emotional, social, cognitive and spiritual aspects (13). Moreover, this concept is influenced by the culture, judgments, people’s status, beliefs, experiences, expectations, and perception(14). In the study titled “A systematic review of analyses of the concept of quality of life in nursing: Exploring how the form of analysis affects understanding," eight critical features of this concept are mentioned, which include being subjective, dynamic, multidimensional, imperceptible, health-related, value-based, interaction-based, and context-based(15).Furthermore, QoL relies on both subjective (qualitative) and objective (quantitative) parameters. Researchers agree that both objective and subjective factors are needed to analyze this concept (16). A QoL instrument should efficiently convert subjective information to objective information and turn information into quantitative and analyzable data(17).

A review of the existing instruments indicates that although various instruments are available for measuring children's QoL, most of them are generic(18). A case in point is the KIDSCREEN 52 item health-related quality of life (HRQoL) questionnaire(19), which is designed by the European Project’s “Screening and Promotion of HRQoL” for children and adolescents in 13 European countries and consists of 10 dimensions, including physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parent relations and home life, social support and peers, school environment, social acceptance/bullying, and financial resources. Moreover, 27-item (20)and 10-item(21) versions of this questionnaire have also been designed. The validities and reliabilities of all the versions have been measured in Iran by Nik-Azin et al. (22-24). In addition, a 35-item QoL questionnaire with one dimension has been designed for 13-18-year-old oncology patients in two versions for adolescents and parents(25). However, no instrument for assessing the QoL of the siblings of sick children was found.

Therefore, considering the significance of this issue in terms of its psychological effects, the disorders it can cause in the development and growth of adolescents with siblings with cancer in cognitive and emotional aspects, and limited nursing knowledge and literature related to measuring this concept, it was deduced that no valid and reliable instrument is available to measure it. Various studies have employed generic instruments to assess this concept (26-30). Developing such an instrument can help us identify physical, psychological, social, economic and educational problems of sick children's siblings and suggest strategies to tackle them. Consequently, the authors decided to conduct a mixed-method study to explore the nature and dimensions of the concept of QoL in siblings of children with cancer, and develop a valid and reliable questionnaire for QoL measurement in adolescents.

Methods

This study is a mixed-method study with exploratory sequential design. It was conducted in four phases: the qualitative study, the integrative review on the studies with similar questionnaires, the item-scale pool development phase and the quantitative study. The study was approved by the Research Ethics Committee of the University (NO: IR.SBMU.PHARMACY.REC.1398.131)

The qualitative study phase

This phase aimed to explore the concept of QoL and its dimensions in siblings of children with cancer. In this phase, 17 adolescent siblings aged 11–20 with a sister or brother younger than 20 years with cancer, four mothers, and four oncology nurses with more than 10 years of experience in oncology wards were selected by purposeful sampling from three university hospitals in Tehran-Iran. Afterward, 25 semi-structured interviews were conducted by an interview guide. Data analysis was done using conventional content analysis with Graneheim &

Lundman's approach (2004) (31). This study has been sent to another journal for publication.

The integrative review phase

This phase aimed to add the necessary items to the extracted items of the qualitative phase. In the integrative review, studies with different methodology can be selected. In this phase, studies consisting of generic and specific questionnaires for measuring child and adolescent QoL were selected using specific key words from different databases of PubMed, Web of Science, Scopus, Science Direct, Ovid, SID, and Google Scholar. The specific keywords were selected from MeSH and they included Psychometry, (Instrument OR measurement OR tools OR questionnaire) (sibling OR sibling relation OR sister and brother), quality of life OR Health-Related quality of life)), (children OR pediatrics), (adolescent OR teenage). An extensive search was done among the studies which were published between 1st of January 2000 and 31st of December 2019 in English and Persian language. Selection of the Studies was done based on the PRISMA 2009 flow diagram.

The item-scale pool phase

The aim of this phase was to develop a primary item-scale pool and prepare the QoL questionnaire for psychometric tests. In this phase, the results of the qualitative and integrative review phases were integrated to create the item scale-pool. Thus, the items of QoL questionnaire were extracted from the results of interviews by the research team members to make the primary item-scale pool. After that, following a review on the generic and specific child and adolescent QoL questionnaires, the necessary items were extracted and added to the primary item-scale pool.

The Quantitative phase

This phase aimed to perform a psychometric analysis on the questionnaire measuring the QoL of siblings of children with cancer. In this phase, a methodologic study with a descriptive design was conducted, and the validity and reliability of the questionnaire were assessed using different tests.

All psychometric stages of this phase were performed by Waltz et al. approach (2010). This approach includes these stages: (1) explaining the concept, (2) determining the development goals, (3) designing a road map, (4) developing the items of the questionnaire and running the psychometric tests, and (5) setting scoring procedures (32).

Face validity

The face validity of the questionnaire was assessed by qualitative and quantitative methods. In the qualitative method, the items' relevancy, difficulty, and ambiguity were evaluated by 10 adolescents separate from the main sample of the study, and 11 experts (in nursing and questionnaire development) from five universities of medical sciences.

In the quantitative method, the item impact score (IIS) was estimated for each item of the QoL questionnaire by 10 adolescents separate from the main sample of the study. The significance of each item was measured and items with an IIS lower than 1.5 were removed.

Content validity

The content validity of the questionnaire was evaluated by qualitative and quantitative methods.

Qualitative content validity of the questionnaire was evaluated in terms of content, grammar, simplicity, clarity of words and proper place of the items based on the opinions of 10 experts in nursing and questionnaire development from five universities of medical sciences.

In quantitative method, content validity ratio (CVR) and content validity index (CVI) of the questionnaire were measured. To measure the CVR, 11 experts from five universities of medical sciences, evaluated the items of the questionnaire as being "necessary," "useful but unnecessary," or "unnecessary." The results were compared to the Lawshe Table. According to the table and number of the experts, the items with a CVR higher than 0.59 (33) were kept in the questionnaire.

Subsequently, to estimate the CVI of the questionnaire, the same 11 experts were asked to assess the items of the questionnaire in terms of relevancy, difficulty and ambiguity, and then score them between1 to 4. According to Waltz & Bausell criteria, items with a minimum score of 0.79, are appropriate, those with a score between 0.70 - 0.79 should be modified, and those with a score lower than 0.70, are unacceptable (32).

In this study, item-content validity index (I-CVI) and scale-content validity scale (S-CVI) were also measured.

After measurement of the I-CVI, the modified Cohen's kappa coefficient index was calculated by assessing the agreement between three evaluator experts. Kappa values higher than 75% show a perfect agreement, those between 60% - 74% show a strong agreement, and those between 40% - 59% indicate an unacceptable agreement (34). Polit & Beck (2010) stated that items with an acceptable Kappa and a CVI of 78% or higher are considered perfect (35).

In the final step of the content validity measurement, six expert panel members, including two researchers and four university faculty members who were experts in nursing and development of tools, were asked to evaluate the comprehensiveness of the questionnaire and its dimensions. They evaluated if the items and their dimensions are match and if there are enough items for the operational definition of the concepts and their dimension.

Construct Validity

Exploratory factor analysis (EFA) was used to determine the construct validity of the questionnaire. A minimum of five samples for each item of the questionnaire is needed for EFA (36). Thus, a convenience sample of 250 adolescents aged 11–20 with a sister or brother younger than 20 years old with cancer was selected to answer the QoL questionnaire with a 5-point Likert scale ranging from 1 (never) to 5 (always). The Kaiser-Meyer-Olkin (KMO) test (≥0.80) and Bartlet's test of sphericity were performed to estimate the adequacy and correlation of the samples. The cut-off point for items was set at 0.40, items with communalities of 0.40 and higher are good to enter to the factor analysis (34). The eigenvalues of one or higher were acceptable. The Scree Plot was used to find the number of factors or dimensions. To determine the structure of the QoL questionnaire, the EFA with the method of Maximum Likelihood and varimax rotation was run.

Reliability

Internal consistency and stability of the questionnaire were evaluated by estimation of Cronbach's alpha coefficient and intra-class correlation coefficient (ICC) to determine the reliability of the questionnaire. Cronbach's alpha coefficients were calculated for the questionnaire and each dimension, separately in the 250 samples to determine the internal consistency. The minimum acceptable Cronbach's alpha coefficient was considered to be 0.70 (37).

A test-retest was run to determine the stability of the questionnaire. Thus, 35 adolescents with a sister or brother with cancer separate from the main sample of the study answered the items of the questionnaire two times at a two-week interval, and the results were estimated by the ICC. In this study, an ICC equal to or greater than 0.80 was considered satisfactory for stability of the questionnaire (38).

Feasibility

In this study, the frequency of responses and non-response items was determined. When the percentage of responders with the minimum and the maximum score for each item (floor and ceiling effect), is less than 15%, the questionnaire has a desirable feasibility (34).

Independent samples *t*-test and one-way ANOVA were also used to check the questionnaire's applicability in both genders and different age groups.

Results

The results of the qualitative phase

Based on the qualitative content analysis, five themes, 11 categories, 26 sub-categories, and a total of 345 codes were extracted from the interviews. It was explored that the QoL of siblings of children with cancer is a relative concept and includes five dimensions: "individual functioning," "struggle to improve the situation," "psycho-emotional status," "family functioning," and "individual health." .

The results of the integrative review phase

In the integrative review of the instruments measuring the quality of life of siblings of children with cancer, 1002 articles were found in databases, and ultimately, the instruments of 34 articles were assessed. As a result of the assessment, 3 items (items 42 to 44) from the WHOQoL-100 and the 12-Item General Health Questionnaire (GHQ-12) were added to the item pool resulting from the qualitative content analysis (39, 40). (figure 1)

The results of the item-scale pool phase

In this phase, 142 extracted items from the qualitative phase and three items from the integrative review were combined and a primary item-scale pool was created. Next, 145 items with a 5-point Likert scale within five dimensions were designed in the research team, and the primary questionnaire was formed. There were 28 items in the dimension of “Individual functioning," 35 items in "Effort to improve the situation," 42 items in "Psycho-emotional status," 26 items in "Family functioning," and 14 items in "Individual health."

The results of the quantitative phase

The results of Face validity

In the qualitative analysis of face validity, based on the opinions of 10 adolescents and 11 experts, nine items needed editing and they were revised. No item was removed of the questionnaire in this stage.

In the quantitative analysis of the face validity, after evaluation of the IIS for each item, 80 items with a score lower than 1.5 were removed, and the number of the items decreased from 145 to 65.

The results of content validity

According to 10 experts’ opinions in the qualitative content validity, no items were removed. In the quantitative content validity, CVR and CVI of the items of the questionnaire were calculated by 11 experts. In the CVR measurement using the Lawshe table, 14 items with a CVR lower than 0.59 were removed, and the number of the items decreased from 65 to 51.

I-CVI values were measured by ranging from 0.75 to 1 for the items. The S-CVI was 0.93 for the questionnaire. Also, the modified Kappa Kohen coefficient index was calculated among the three evaluator experts. Six items (5 of which overlap with the items removed in the CVR analysis) with unacceptable agreement levels were removed. Therefore, only 1 item was removed in this stage, and the number of the items decreased from 51 to 50.

In the final step, six expert panel members assessed the comprehensiveness of the questionnaire, and three items, including "I have enough time to do my homework," "I have to accept the circumstances," and "I am optimistic toward my sick sibling’s recovery,” were omitted due to overlap with other items. Moreover, a single item in the dimension of “Individual health” (my mental and physical health depends on my sick sibling’s health) was moved to the dimension of the “Psycho-emotional status" because of similarity with the rest of the items in that dimension. Also, it was not possible to analyze a single item in factor analysis, and thus the dimension of "Individual health" was omitted.

As a result, a questionnaire with 47 items and four dimensions of "Individual function," "Effort to improve the situation," "Psycho-emotional status," and "Family functioning" remained for the assessment of the construct validity in the next step.

The results of the EFA

In this step, a convenience sample of 250 adolescents aged 11-20 with a sister or brother with cancer was selected to answer the demographic and clinical characteristics questionnaire and the QoL questionnaire of siblings of children with cancer (a questionnaire with 47 items and four dimensions using a 5-point Likert scale ranging from 1 to 5, never to always). Objectives of the study and confidentiality of the information were explained to the adolescents and their parents. The adolescents and their parents both completed the informed consent forms. The adolescent's demographic and clinical characteristic is presented in Table 1.

The results of the KMO test (0.846) and Bartlett's test of sphericity ($df = 1081$, $\chi 2 = 5439.372$, $P < 0.000$) were satisfactory.

In the EFA, the correlation matrix was created, and the latent factors in the questionnaire were uncovered using main factor analysis and varimax rotation (Table 2).

The EFA extracted factors based on an eigenvalue higher than 1 and cumulative variance. Accordingly, six latent factors with an explained variance of 10.62%, 10.55%, 8.25%, 7.66%, 6.70%, and 5.26% were extracted. The total explained variance of the data was 49.05%. The scree plot also confirmed these factors (Figure 2.).

Who answered the items of the factor loading of the items was not lower than 0.40 in any of the six extracted factors based on the matrix table of the factors rotated by varimax rotation. However, the item "my mental and physical health depends on my sick sibling’s health,” did not correspond to any factor and was therefore removed. At last, 46 items were kept in this stage. Afterward, each factor was named based on the items (Table 2). The six dimensions resulting from the EFA were: "adaptation to conditions" (10 items), "psycho-emotional functioning" (13 items), "individual functioning" (7 items), "illness burden on the family" (5 items), "daily life challenges" (7 items), and "spiritual adjustment" (4 items). Data analysis was performed using SPSS 20 (IBM Corporation, Armonk, NY, USA).

The results of the reliability

The internal consistency of the questionnaire was measured by calculating the Cronbach's alpha coefficients on 250 adolescents QoL questionnaire. The Cronbach's alpha coefficient of the questionnaire was 0.93. Also, it was ranged from 0.77 to 0.88 for the dimensions of the questionnaire (Table 3).

To evaluate the questionnaire's stability, ICC was measured twice with a two-week interval in 30 adolescents with similar characteristics to the main sample. The ICC of the questionnaire was 0.80. Also, it was ranged from 0.84 to 0.95 in dimensions of the questionnaire (Table 3).

The results of the Feasibility

The value of the floor and ceiling effect was smaller than 0.15 in the questionnaire and its dimensions, indicating appropriate feasibility (Table 3).

The independent *t*-test results showed no significant difference between the mean scores of QoL in girls or boys siblings ($P < 0.149$). According to one-way ANOVA, no significant difference was observed between the mean scores of QoL based on the siblings' age ($P < 0.506$) (Table 2). Therefore, this questionnaire showed feasibility and can be used for different genders and age groups.

Quality of Life Questionnaire for Siblings of Children with Cancer

In this study, a valid and reliable questionnaire was developed to assess QoL of siblings of children with cancer. This questionnaire is a specific self-reported instrument with 46 questions and six dimensions and a 5-point Likert scale ranging from always (5), to never (1). The raw scores range from 46 to 230. After calculating the raw scores, they are transformed to 0-100. Higher scores indicate a better QoL.

Discussion

This study aimed to develop a questionnaire to assess the QoL of siblings of children with cancer and perform a psychometric analysis. The study included four phases, the qualitative phase, integrative review, item-scale pool development, and psychometric phase. After the item-scale pool development and psychometric tests, a valid and reliable QoL questionnaire with 46 items and six dimensions, including "adaptation to conditions", "psycho-emotional functioning", "individual functioning", "illness burden on the family", "daily life challenges", and "spiritual adjustment" was developed. The comprehensive search for texts indicates that this instrument is the only instrument for measuring the QoL of siblings of children with cancer, and there is no such questionnaire, at least in English or Persian language.

Numerous generic and specific instruments have been developed to measure children and adolescents' quality of life. One of the generic QoL instruments is the 23-item Pedsql-Generic Core questionnaire with four dimensions, including physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items) (41). The specific Questionnaire Peds QL Cancer Module for children (25 items) and adolescents (27 items) has also been developed with five domains of treatment, psychological, emotional, social, and cognitive complications (42). In the present study, psycho-emotional functioning with 13 items was one of the instruments' dimensions. Considering the theme of "general health" in the qualitative phase, it seems that due to the "physical well-being" of the study population, the dimensions of physical functioning and treatment complications did not emerge in the present study. However, "school functioning" was placed in the "individual functioning" dimension.

In the qualitative and quantitative face validity analysis, the items were revised, modified or removed based on the opinions of the adolescent target group, experts in nursing and questionnaire development, and the item impact score (IIS). In the qualitative and quantitative content validity analysis, some phrases were modified or removed by calculating the CVI, CVR, and coefficient of agreement, and, finally, the assessment of the comprehensiveness of the instrument by the expert panel, and 47 phrases entered the construct validity analysis. Mohammadian et al. evaluated the validity of PedsQL in the city of Kashan, Iran. The instrument's CVI was 0.84, and the CVIs of the physical, emotional, social, and school functioning sub-scales were 0.80, 0.86, 0.83, and 0.88, respectively(43).

EFA was performed for 250 participants. In this model, based on an eigenvalue higher than 1 and cumulative variance, six latent factors with factor loadings less than 1 and variances of 10.620, 10.555, 8.251, 7.661, 6.703, and 5.265 were extracted. Reio et al. (2015) stated that if the factors identified in a factor analysis explain at least 40% of the total variance (44), and each factor explains 5% of the total variance(45), the instrument's construct validity is confirmed.

According to the study conducted by Amiri et al., EFA with a varimax rotation led to the extraction of six factors from the PedsQL™ 4.0 for both self-report instruments of children 8 to 12 years old and their parents, which made up 47.9 and 54.8% of the total variance. The KMO values (0.71 and 0.74) and the significance of Bartlett's test of sphericity in children and parents confirmed the adequacy of the sample (46).

In this study, the internal consistency of the instrument and its dimensions (0.931) was satisfactory. Stability reliability was measured through ICC measurement, and the total ICC was higher than 0.8, which was satisfactory. The study conducted by Hadinfard et al. (2021) aimed to assess the psychometric characteristics of the Farsi version of PedsQL 4.0 on 326 adolescents (12–17 years old); they reported internal consistency of 0.8–0.83 for the dimensions and 0.92 for the scale as a whole, and the test-retest reliability of the scale was reported to be 0.87 (47). In the study conducted by Ji et al. (2011) titled "Measuring health-related quality of life (HRQoL) in children with cancer living in mainland China: feasibility, reliability, and validity of the Chinese mandarin version of PedsQL 4.0 Generic Core Scales and 3.0 Cancer Module," Cronbach's alphas for the generic questionnaire and cancer scale were higher than 0.7 in the self-report and parent report. The test-retest reliability check in the generic scale of PedsQL 4.0 in children with cancer or their families showed a correlation of 0.61–1 in a period of one to two weeks (48). In the study by Mohammadian et al., the correlation coefficient between the children's PedsQL and its four sub-scales was also acceptable ($r > 0.7$) (43).

The mean scores of QoL of siblings of children with cancer were not different between girls and boys. This proves the usability of the instrument for both genders. Moreover, since there was no significant difference between the mean scores regarding age, the questionnaire is suitable for adolescents.

One of the present study's limitations was that it was limited to adolescents. Siblings are affected by the psychological and physical side effects of a family member's cancer. Therefore, it is suggested that a similar instrument be developed for children aged 8-12 who have siblings with cancer. However, the information collection methods in the qualitative phase depend on the interviewer's mastery in using methods for interviewing children and in drawing and playing analysis. Validation of the present instrument is recommended in other populations.

Conclusions

This study resulted in a specific self-report questionnaire measuring the QoL of siblings of children with cancer, including 46 questions and six dimensions of "adaptation to conditions", "psycho-emotional functioning", "individual functioning", "illness burden on family", "daily life challenges", and "spiritual adjustment".

After achieving appropriate validity and reliability, we can use this instrument in different age groups. This instrument is developed for adolescents aged 11–20.

Sibling's cancer creates challenges for an adolescent who is in the growth and development stage of life, especially in terms of identity formation, who likes to interact with peers, participate in sports groups, and interact with school and society, who is ready to study in higher levels, and who needs an environment filled with security, peace, and affection. If these needs are not met, they will face despair, depression, anxiety, social anomalies, loneliness, dependence, and academic failure. The findings of this study, which classified adolescents' quality of life into six categories, indicated the crucial aspects of this issue that had not been discussed.

Ethics declarations

This study has been approved by the Research Deputy of Shahid Beheshti University of Medical Sciences with the ethics code 1129.1397.REC.RETECH.SBMU.IR and was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all participants.

Competing Interests

None.

Statements and Declarations

Competing interest

This study has been approved by the Research Deputy of Shahid Beheshti University of Medical Sciences under the ethics code No: IR.SBMU.PHARMACY.REC.1398.131 and was conducted in accordance with the Declaration of Helsinki.

Conflict of interest: None declared

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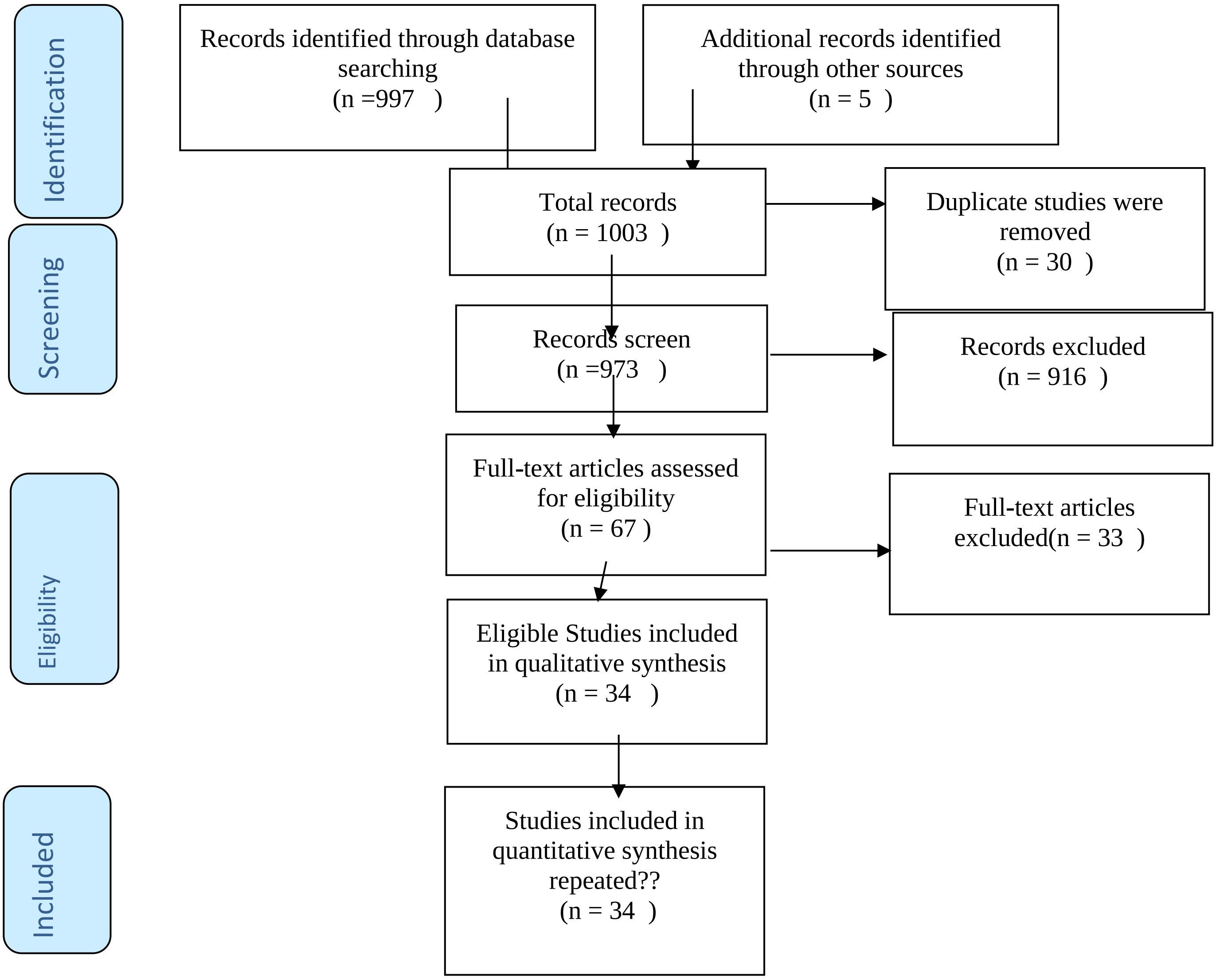

Figure 1: Studies selection method based on the PRISMA (2009)

Table 1: The demographic and clinical characteristics of the adolescents (n = 250)

Variable		**n (%)**
Gender	Female	122 (48.8)
	Male	128 51.2)
Father’s education	Illiterate	8 (3.2)
	Under high school diploma	84 (33.6)
	High school diploma	127 (50.8)
	University degrees	31 (12.4)

Mother’s education	Illiterate	6 (2.4)	
	Under high school diploma	79 (31.6)	
	High school diploma	139 (55.6)	
	University degrees	26 (10.4)	
Father’s occupation	Unemployed	2 (0.8)	
	Worker	77 (30.8)	
	Clerc	96 (38.4)	
	Retired	26 (10.4)	
	Self-employed	49 (19.6)	
Mother’s occupation	Homemaker	104 (41.6)	
	Working	117 (468)	
	Retired	29 (11.6)	
Household monthly income (Toman)	Less than 4 million	1 (0.4)	
	4-6 million	34 (13.6)	
	More than 6 million	215 (86)	
Ill sibling’s cancer	Leukemia	119 (47.6)	
	Lymphoma	30 (12)	
	Sarcoma (Osteosarcoma and Rhabdomyosarcoma(	14 (5.6)	
	Wilms' tumor	14 (5.6)	
	Malignancy in the eye or central nervous system	45 (18)	
	Other types (Malignancy in the thyroid, liver, or digestive system)	28 (11.2)	
Injury, wound,or inflammation on the hands	Yes	116 (46.4)	
	No	134 53.6)	
Variable		**Mean**	**Standard deviation**
Age (years)		41.15	69.2
Ill sibling’s age (years)		76.71	78.2
Duration of ill sibling’s cancer (months		06.11	21.7

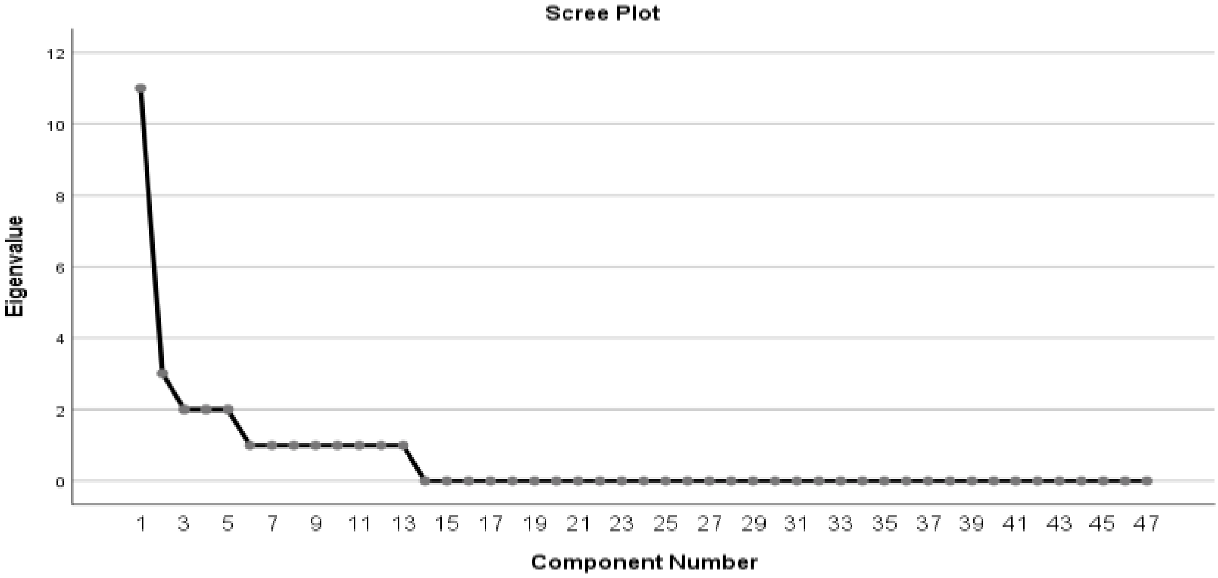

Figure 2: The scree plot, eigenvalue, and factors extracted from the quality of life of siblings of children with cancer questionnaire

Table 2: The matrix of factors rotated with varimax rotation and factor loading of the items for each factor

Number	Items	Factor loading					
		1	2	3	4	5	6
1	I try to raise my parents' and the ill sibling's spirit.	69.0					
2	I like to help my parents.	67.0					
3	I give up the pleasures of adolescence due to the current situation in my family.	64.0					
4	I like to please my ill sibling.	64.0					
5	I try to tolerate the difficulties to help my family.	64.0					
6	My sense of independence has improved.	63.0					
7	I adapt myself to the current economic status of the family.	63.0					
8	I try to provide more facilities for my ill sibling.	59.0					
9	Our relatives support my family.	58.0					
10	I want to solve my problems myself.	57.0					
11	I feel sorry for my ill sibling.		66.0				
12	I keep unpleasant thoughts out of my mind due to my love for my ill sibling.		66.0				
13	I have accepted the new condition and I am thankful to God.		66.0				
14	I feel attached to and dependent on my ill sibling.		60.0				
15	I am sad because of the chemotherapy side effects my ill sibling suffers from.		58.0				
16	I feel happy when I help my ill sibling do their homework.		58.0				
17	I am worried about my ill sibling’s future.		55.0				
18	I hide my feelings from my ill sibling.		54.0				
19	I feel uneasy in this situation.		52.0				

20	I am afraid of losing my ill sibling.		50.0				
21	I feel satisfied with my life.		49.0				
22	I am optimistic about my ill sibling's recovery.		53.0				
23	I need my friends’ empathy.		42.0				
24	I feel responsible for my ill sibling.			75.0			
25	My interactions with my friends have decreased due to my sibling’s illness.			72.0			
26	I spend a lot of time with my sibling at home.			67.0			
27	I understand my parents’ feelings when my sibling is ill.			65.0			
28	I understand my family’s condition during my sibling’s illness.			60.0			
29	I have enough time to do my homework.			56.0			
30	I have enough time to participate in extra-curricular classes.			55.0			
31	My parents’ behavior has changed in these conditions.				77.0		
32	This situation has caused a heavy financial burden on the family, on especially my father.				76.0		
33	My parents experience a heavy emotional burden caused by my sibling’s illness.				65.0		
34	My family’s financial ability has deteriorated due to the treatment costs of my sibling's illness.				64.0		
35	My parents support me in these times.				58.0		
36	My mental and physical health depends on my ill sibling’s health.						
37	There is happiness in my family.					70.0	
38	My routine life is being challenged.					69.0	
39	My family’s lifestyle has changed to help my ill sibling’s recovery.					68.0	
40	My friends understand my situation.					57.0	
41	I try to keep my spirit high, stay calm, and healthy.					57.0	
42	I am provided with my routine needs, such as food and clothing.					50.0	
43	I understand my physical health better.					59.0	
44	I talk to God about my problems.						80.0
45	I pray for my ill sibling’s recovery.						66.0
46	I believe in God’s help.						63.0
47	I listen to music to keep calm.						53.0

Table 3: The reliability results of QoL questionnaire by Cronbach’s alpha coefficient and Intraclass correlation coefficient (ICC) among 250 adolescents

Questionnaire	**Cronbach’s alpha coefficient**	**The number of items**	**ICC**	**Confidence interval 0.95**	**P-value**	**Floor effect *n* (%)**	**Ceiling effect *n* (%)**
Adaptation to	88.0	10	88.0	93.0–81.0	1	11	0

conditions						(4.4)	
Psycho-emotional functioning	85.0	13	90.0	94.0–84.0	1	2 (8.0)	0
Individual functioning	83.0	7	84.0	91.0–74.0	1	16 (4.6)	0
Illness burden on family	84.0	5	86.0	93.0–77.0	1	14 (6.5)	0
Daily life challenges	79.0	7	88.0	93.0–80.0	1	2 (8.0)	0
Spiritual adjustment	76.0	4	86.0	93.0–75.0	1	22 (8.8)	0
Total	93.0	46	95.0	97.0–92.0	1	0	0

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