

Quality of Life Experiences in Siblings of Children with Cancer: A Qualitative Content Analysis

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Abstract

Background

Having a child with cancer in the family can be a stressful, unpredictable and uncontrollable experience. This stressful condition brings about changing in the family structure, communications, values and roles and disrupt family members' quality of life (QoL), especially siblings. This qualitative study aimed to explore the experiences of QoL in the siblings of children with cancer.

Methods

This is a qualitative content analysis study which was conducted from October 2020 to April 2021. The participants included 17 siblings of children with cancer in the oncology wards, four parents and four nurses who were selected through purposive sampling from four pediatric university hospitals in Tehran-Iran. The data were collected using semi-structured in-depth interviews and were analysed through conventional content analysis method by MAXQDA version 2019. To check the rigor of the study, several approach were used, including member and external checks, maximum variation, in-depth data analysis and accurate recording and transcribing.

Results

Five themes, 11 categories, 26 subcategories and 345 codes were obtained from the data. Based on the participants' experiences, five dimensions of QoL were extracted for siblings of children with cancer, namely "individual function", "effort to improve the situation", "psycho-emotional function", "family function" and "individual health".

Conclusions

The experiences of our participants clarified various dimensions of the multidimensional concept of QoL in siblings of children with cancer. It can be a platform for further research, development of specific scale and planning interventional studies.

Background

Chronic disease is a long-lasting or recurring condition that disrupts a child's daily activities and lasts longer than three months (1). One of the important chronic diseases of children are cancers, which affect their live for a long time (2). Cancer can be a stressful, unpredictable and uncontrollable experience that creates challenges for family members. It can impacts on the family structure and roles and disrupts the functions of family members, especially those of healthy siblings. Financial, physical and emotional needs of the families increase and may the families require adapting their plans to the child's treatment

process (3). Compared with their peers, these siblings face unique situations that may positively or negatively impact their current or future health (4). Negative impacts include internal problems (depression, anxiety, sorrow, despair, loneliness), external problems (economic and social problems, aggression, and anger), physical disorders (sleep disorders and eating behaviors), and disorders in psycho-social adaption (5). These siblings consider themselves forgotten members of their families and, like the diseased child, might experience notable changes in their daily functions (6). They have also stated limitations in family life (feeling of loneliness and lack of attention from the parents), social life (negative public perception and its effect on relationships with peers), and delays in their growth and development (5). Childhood cancer and its treatment can significantly affect the child, their parents, and their siblings' psychological and social adaptability (7); it also affects their Quality of Life (QoL) (8). QoL includes physical, psychological, and social health in different aspects of life, such as physical activity, memory, attention, sleep, and participation in social activities. It is deeply affected by people's experiences, expectations, and perceptions (9, 10). Since patients' QoL is interrelated with family members, both must be considered (11). QoL is a concept and construct affected by context. This multidimensional concept includes cognitive, physical, emotional, social, and spiritual aspects (12) influenced by culture, judgments, people's positions, beliefs, experiences, expectations, and perceptions (13). The World Health Organization (WHO) defined QoL in 1994 as "people's perception of their position in life in terms of the culture and value systems in which they live and in, their expectations, standards, and priorities; it is personal, cannot be observed by others, and is based on people's perception of different aspects of their lives (14). Nursing scholars have also provided some definitions for QoL. Peplau considers the concept of QoL as an intangible and comprehensive concept and defines it as individuals' mental perception of his life and synonymous with mental well-being or health, which is often associated with health (15). Researchers agree that subjective and objective indices are required to measure the QoL (16).

In a study on adolescent siblings of children with cancer from a salutogenic health promotion perspective, Løkkeberg et al. extracted "new challenges and needs in everyday life" as the main theme and "cancer into life" and "helpful resources to cope" as two dimensions (17). Havill et al. analyzed siblings' behavioral patterns aiming to assess the application of the grounded theory in siblings' responses to children's cancer in a broader range of childhood circumstances and revise the existing theory in order to reflect the participants' experiences; the results confirmed the adaptation patterns of "changes in personal and familial life" and "efficient management in these conditions" (18).

Kaatsız et al., in a qualitative study titled "I'm Here, too: Being an Adolescent Sibling of a Pediatric Cancer Patient in Turkey," reported three themes based on interviews with adolescents. The main theme was "I am here, too." From the moment of diagnosis, siblings need to be acknowledged by others (parents, healthcare specialists, friends, etc.). They were looking for ways to understand the disease since they experienced considerable changes in all aspects of their lives. Therefore, they expected their parents and relatives to support them and tried different methods for confronting the changes.

Although, there are various definitions and models of QoL such as Wilson and Cleary's model and its revised version (19), the concept of QoL in siblings of children with cancer is complex and the impact of cultural context on QoL cannot be ignored. Thus, this study aimed to explore the experiences of QoL in siblings of children with cancer in order to find its definition and dimensions.

Methods

Design, setting and sampling

The present study is a qualitative content analysis study which was conducted from October 2020 to April 2021. This study is part of the first author's doctoral thesis aiming to develop a specific scale to assess the QoL in siblings of children with cancer. The study participants were entered to the study by purposive sampling. They included 17 siblings of children with cancer younger than 20 in the oncology wards of four pediatric university hospitals in Tehran-Iran. After data collection in siblings, four mothers and four nurses were also interviewed to rich the data. Purposive sampling was used, and it continued until data saturation. The inclusion criteria for siblings of children with cancer included being a sibling in 11-20 years old and having a sister or brother with cancer younger than 20 which his/her diagnosis confirmed by a specialist. The mothers had two children at least and one afflicted with cancer. The inclusion criterion for nurses was having work experience more than 10 years in pediatric oncology wards and outpatient chemotherapy clinics.

Data collection

Data collection was done by the first author through semi-structured in-depth one-to-one interviews in a calm and quiet place in the hospitals at an appropriate time for participants. The interviews were recorded using an mp3 recorder after acquiring permission from the participants. The interviews started through an interview guide with a general open-ended question and continued based on the answers. The interview questions included "Could you please explain your experience as a sibling of a child with cancer? ", "Could you please describe your current general condition? ", "How would you describe your QoL considering having a child with cancer?", and "What have you experienced in your family during this time?" Follow-up questions based on the information provided by the participants and deepening questions, such as "Explain more," "What do you mean?", and "Can you give me an example so I can understand better?", were also asked to clarify the subject matter. Furthermore, the non-verbal or verbal responses of participants were recorded on a paper by the first author. The interviews lasted for 20-45 minutes. Data saturation occurred when no new category emerged, the categories reached saturation in terms of features, and the relationship between them was well developed.

Data analysis

After each interview, the recorded materials were carefully transcribed word by word. Analysis and primary coding of each interview, were performed before the next interview. In this method, called the inductive model, the researcher allows the categories and their names to emerge from the codes. After

each interview, the recorded information was listened carefully as soon as possible, and it was then typed into the software. Subsequently, the texts were read several times so that the researcher would develop a new general idea by being immersed in the data.

Data analysis and the extraction of main codes and themes were done using Graneheim and Lundman's approach (2004) (20) by MAXQDA-2019. Qualitative analysis was done in five stages, including 1) Transcribing interviews immediately after conducting them, 2) Reading full texts to get a general understanding, 3) Determining meaning units and primary codes, 4) Categorizing the similar primary codes in more comprehensive categories, and 5) Determining the main theme in the categories.

The rigor of the study

Lincoln and Guba (1985) suggested credibility, dependability, confirmability, transferability and authenticity as the five indices of rigor (20). In the present study, to check the credibility and clarify the codes, the texts and their codes were given to three external referees with doctoral degrees in nursing who were experts in qualitative research so that they would check the correspondence of the codes and categories with the text of the interviews and express their opinions. Moreover, the dependability and confirmability of the data were strengthened through recording the accurate data and revision of it. When codes were not in line with the participants' opinions, they were reviewed and revised. In this study, the maximum variation of the participants in terms of age and gender was maintained. Data saturation and transferability were achieved by the proper explanation of the study context, selection of participants, data collection, analysis, and in-depth description of the findings. Furthermore, the findings were presented thoroughly and logically and accurate recording and transcribing led to the trustworthiness and rigor of the data.

Results

The mean age of the adolescent siblings in the study was 14.2 ± 3 years old. Moreover, 64% were female, 93% were the first child in the family and 82% of the families had two children. The mean age of children with cancer was 8.25 ± 2.65 years old. Furthermore, 64.7% were female and 82.3% had Acute Lymphoblastic leukemia diagnoses. The mean time passed from their diagnosis was 20.17 ± 15.18 months. The mothers who participated in the study were aged 38 ± 2.38 . The nurses were 40.75 ± 3.09 years old and had 13.2 ± 5.38 years working experience in the pediatric oncology wards.

Qualitative data analysis on experiences of the siblings of children with cancer showed that QoL is a relative concept with five themes, 11 main categories, 26 subcategories, and 345 codes (158 non-duplicate codes). The extracted themes included "individual function", "effort to improve the situation", "psycho-emotional function", "family function", and "individual health". The categories and subcategories are presented in Table 1.

Theme 1: Individual function

Each person, as a whole, has unique qualities in terms of characteristics, spirituality, relations, and interests in general. From the perspective of adolescent siblings of children with cancer, the individual function was crucial for their QoL. Three main categories of responsibility, interaction with people, and educational status were extracted from this category's data. The category of responsibility included subcategories of participation in care (accompanying the child while hospitalized, spending time with the child at home, etc.) and commitment to the integrity of the family (feeling responsible for parents and the sick child).

"For instance, I help my mom clear the tablecloth. I organize my brother's toys. I wash the dishes sometimes. I clean the house. That's because my mom works a lot and I feel it's not fair." (P 4)

"I realized it is my duty, and I have to spend more time with my parents. My brother needs me more now since my mom is not herself anymore and my father is even worse." (P 2)

Table 1: Themes, categories, and subcategories of QoL in siblings of children with cancer

Theme	Main category	Subcategory
Individual function	Responsibility	Participation in care
		Feeling of commitment
	Interaction with people	Relations with friends
		Sympathy for the family
		Social relations
	Educational status	The challenge of being in the educational environment
		Educational outcomes
Effort to improve the situation	Adapting to the situation	Spiritual adaptation
		Individual adaptation
		Efforts to improve the family's condition
	An effort to keep a balanced life	Caring about one's self
		Paying attention to leisure time
		Attracting social support
Psycho-emotional function	Emotions	Emotional reactions
		Socio-emotional reactions
		Emotional reactions to the sick sibling
	Range of feelings	Pleasant feelings
		Unpleasant feelings
Family function	Instability in the family	Changing the family's routine
		Disturbances in the family
	Meeting the needs	Family's economic vulnerability
		Familial support
Individual health	Signs and symptoms	Nervous systems symptoms
		Cardiovascular symptoms
	General health and nutrition	General description of health status
		Nutrition

In the domain of interaction with people, subcategories of relations with friends (poor relations with friends due to the disease, preserving proper relations with friends, etc.), sympathy for the family (understanding the family's situation, understanding the sick child's situation, etc.), and social relations (reducing contact with relatives and establishing proper relations with other people in society) were stated as other factors affecting the QoL; in this regard, they said:

"I have good relationships with my friends. They understand me. I can't keep up, but they bring me their notebooks and tell me to write the things I have missed without my having to ask them. They care for me. My friends try to be around me so that I do not think about my brother." (P 2)

"When my sister had infusions here and took her medicine, I tried to make her laugh when she came back home; I tried to make her happy so that her condition would not affect her. For instance, now that she is going to be under anesthetic drugs, I try to make her laugh and change her mood." (P 11)

"In terms of social relations, everything is fine. When I go somewhere, everyone is so welcoming. When I go to my aunt's or uncle's, they treat me really well." (P 8).

In terms of educational status, the participants' opinions were quite thought-provoking; they stated its effect on the QoL in the subcategories of the challenge of being in the educational environment (unwillingness to participate in classes, obligatory absences due to the sick child's treatments), and educational outcomes (delays in doing homework due to accompanying the sick child, insufficient time to participate in extracurricular classes, lack of concentration in learning, educational decline, etc.). They stated:

"I do not go to school anymore; I have not been able to study. I have missed school because of my sick brother." (P 1)

"Coming for chemotherapy has affected my studies. I cannot go to school on Wednesdays. I have problems in Arabic. I cannot find the time to study." (P 4)

"When my brother got sick, no one was at home, so I stayed with my aunt for a while. My father visited me there. After a while, I returned home; once again, I went to stay with my aunt, and I could not study there." (P 1)

"There is something about education; education is part of my soul. Now, I need to go to private classes to be able to answer MCQs and achieve good results." (P 10)

Theme 2: Effort to improve the situation

When a child develops cancer, their family, especially their young siblings, face numerous problems. Each person uses specific ways to overcome these problems and reduce psychological and physical harm in this critical situation. The participants in the present study pointed to ways to cope with the situation and efforts to maintain a balanced life. To adapt to the situation, they had used spiritual adaptation (talking

to God, believing in God's help, reading the Quran, etc.), individual adaptation (adolescents accepting themselves to contribute to the family's adaptation, adolescents' adaptation to the economic situation of the family, increase in independence, problem-solving, etc.), and efforts to improve the family's conditions (trying to make the family happy, keeping the sick child's spirit high, etc.).

"I pray, and I trust in God. I try not to do things that add to my family's problems so that they can have better control over the situation." (P 14)

"For instance, when something bad happens, I try to cope with it first and then help others. Therefore, I believe this is my new role: to be a stronger girl than four years ago and try to be happier. Now, everyone sees me as someone with high spirits trying to give hope to others." (P 5)

"I have to prevent my brother from becoming sad and angry as much as possible. That is because he cannot go out or even eat ice cream outside the house. In short, I support him in my own way." (P 12)

When trying to keep a balanced life, caring about oneself (efforts to keep calm and maintain high spirits, etc.), paying attention to leisure time (exercising, having fun, playing, etc.), and attracting social support (support from friends, teachers, etc.) helped the participants adapt to the situation at hand.

They stated their efforts as follows:

"First of all, I thank God and then my family for this spirit I have; I also owe this spirit to singers; I want to become a singer myself; I also like to be a football player in the future. However, it mostly comes from the family and those who are with me. If they are happy, we are happy. Thank God." (P 16)

"We exercise; we have fun; I have my own hobbies." (P 12)

"All my father's family turned their backs on us, but his friends helped us; they lent us money so that we could sell our old car and buy another one." (P 15)

Theme 3: Psycho-social function

People have different psychological and emotional reactions to different situations. In this study, adolescents with a sibling with cancer thought psycho-social factors were effective on their QoL. Two main categories of "emotions" and "range of feelings" emerged in this dimension. In the category of emotions, subcategories of emotional reactions (crying, isolation, looking for an excuse for happiness in themselves and their families, mood changes based on the sick child's condition, etc.), socio-emotional reactions (fear of friends' pity, feeling sad due to classmates' lack of understanding, paying attention to social relations, etc.), and emotional reactions to the sick sibling (feeling sad for the child, feeling sad about talking to the child, fear of losing a brother, refraining from suicide due to the love for the sick sibling, etc.) were stated:

"We are not Okay; we are always anxious and stressed, but we try to keep our spirits high because of the child; however, the fear and anxiety are always with us." (P 2)

"Sometimes when some kids in the class say that children with cancer do not get well, I become extremely sad." (P4)

Regarding the range of feelings, subcategories of pleasant feelings (happiness, joy, satisfaction with life, etc.) and unpleasant feelings (feeling of nostalgia due to being far from the family, lack of peace, loneliness, depression, etc.) affected the participants' socio-emotional function:

"We are a good family. However, some people might have a sick family, or they might not like their families." (P 16)

"My parents are a mess. My brother's disease has lasted for a long time. He is often hospitalized. His cell count keeps falling. I have not seen him for a long time, and whenever he is home, he is sick. I feel pity for him. God help him." (P 1)

Theme 4: Family function

Family plays a notable role in people's life satisfaction in childhood and adolescence. Adolescents who had siblings with chronic diseases also stated this fact. Two categories of "instability in the family" and "meeting the needs" were mentioned in the dimension of family function. In the category of instability in the family, subcategories of changing the family's routine (migration for treatment, being far from the mother and home, interferences in the father's job, etc.) and disturbances in the family (bullying by the sick child, unhappiness in the family, moodiness, changes in parents behavior toward each other, etc.) emerged, and the participants stated:

"My father does not go to work at all and has put someone in his place as a substitute; he only visits his workplace from time to time; he says he is not in the mood for working." (P 2)

"Yes, I am sad. Nothing is certain. No one is home. The food is never ready. We do not play or go to the park; I need lots of things." (P 1)

In the category of meeting the needs, two subcategories of family's economic vulnerability (heavy financial burden of the disease on the family, especially the father, reduction of financial ability due to the treatment costs, etc.) and familial support (support of the adolescent by the father, treating children equally, more attention to the adolescent's physical health, etc.) emerged, and the adolescents stated:

"I need many things, but whenever I tell my father, he says I do not have money. I feel terrible. I have no one. No friends." (P 1)

"My mother attends to me and my studies too. They do everything for me. I know my brother's condition is different, but she does not discriminate between him and me." (P 6)

Theme 5: Individual health

Normally, one family member's chronic problems can cause some physical problems for other members. In the present study, the siblings of children with cancer pointed to this, and two main categories of "signs and symptoms" and "general health and nutrition" emerged. In the category of signs and symptoms, the subcategories of nervous system symptoms (headache, dizziness, distraction, etc.) and cardiovascular symptoms (hypotension, tachycardia, etc.) were reported, and the adolescents stated:

"There are some problems here; there is so much crying that it causes blood pressure to suddenly drop."
(P 2)

Moreover, in the category of general health and nutrition, two subcategories of "general description of health status" (fatigue, lethargy, sickness, irritability, etc.) and nutrition (anorexia, family's attention to the improvement of all children's nutrition) were extracted, and the participants stated:

"Our nutrition has improved; since Mahna needs better nutrition, we get better food too." (P 7)

Discussion

The present study explored the main factors of QoL in adolescent siblings of children with cancer. The research findings included five main themes of "individual function", "effort to improve the situation", "psycho-emotional function", "family function", and "individual health" in the study population.

"Individual function" refers to the study population's QoL, responsibility, interaction with others, and educational status. Similar to the present study, the participants in the exploratory study conducted by Løkkeberg et al. expressed increased responsibility as well as empowerment as subcategories of "growing up" from the "cancer into life" dimension (17). Moreover, in their study, Kaatsiz et al. extracted the category of "growing up suddenly" in the theme of "change in life." They stated that changes in family routines impose more responsibility on the participants. In addition, taking care of sick siblings, housekeeping, or cooking limit their social life and even prevent them from spending time on themselves (21).

In these families, due to the absence of parents and their involvement in the treatment process of their sick child, healthy siblings often stay home alone and are forced to take care of their own nutritional needs and even do some household chores. Therefore, they have more responsibilities than before. In a qualitative study, Prchal et al. explained siblings' experiences of children with cancer after diagnosis. They extracted the dimensions of the ill child, family life, peers, school, and hospital from the participants' data. In the dimension of family life, the siblings pointed out the household chores such as cooking and cleaning and the absence of parents. Although healthy siblings did not do these chores voluntarily, they did not complain about the situation and saw it as a way to help their parents (22). Moreover, in the present study, participation in caring for the sick sibling at home or in the hospital was a sign of commitment to the family. Toft et al. reported similar results and demonstrated two categories of interpersonal experiences following a cancer diagnosis in a sibling, "feeling excluded while wanting to maintain a relationship with their ill sibling and being involved in the care" and "feeling stigmatized and

exposed in social contexts while needing an allowing space to talk about their experiences” (23). Prchal et al. also noted in their findings in the dimension of “hospital” that caring for sick siblings in the hospital was beneficial to the healthy siblings in many ways. They described going to the hospital as a good opportunity to get to know the hospital environment and get a real picture of the sick child's medical condition and, therefore, better cope with the situation. They brought food to the hospital and helped with daily chores. It was essential for most families to be in that environment and help. However, some healthy siblings also pointed out that sometimes it was difficult for them to understand when and how to help (22). Interacting with others such as their friends, peers, families, and relatives can help them spend their leisure time, practice empathy, and express their emotions. Based on the subcategory of “open and empathic communication” in the categories of the theme of “expectation” from the perspective of the participants in the study conducted by Kaatsiz et al., adolescents expected their parents and others around them (friends, teachers, relatives, neighbors, and healthcare professionals) to have a better understanding of the situation. They even considered these interviews supportive and a way to talk about and express their feelings (21). In their study, aiming to investigate the quantitative and qualitative nature of QoL in siblings of children with cancer in summer camps, Packman et al. extracted the six themes of “group cohesiveness,” “development of socializing techniques,” “universality,” “instillation of hope,” “interpersonal learning,” and “catharsis” based on an interview consisting of 15 open-ended questions with the participants. Interaction with people improves social relations, social learning, social skills, and relationships with peers and leads to meeting new people. In the present study, the participants included “relations with friends,” “social relations,” and “sympathy for the family” in the category of “interaction with people.” When Packman et al. asked the siblings in the camp, “What was your favorite thing about the camp?” they answered love, acceptance, and good understanding (24). In the category of “educational status,” the siblings of children with cancer mentioned two important concepts of “the challenge of presence in the educational environment” and “educational outcomes.” At first glance, it seems that a sibling's cancer does not affect school and learning activities. However, gradually the sibling will face many problems. In this regard, Prchal et al. mentioned “academic success,” “hatred of school,” and “questions at school” in the dimension of “school.” Academic decline was reported in many healthy siblings due to being worried about their siblings' illness and the changes in their homes' condition. They tended to miss school to support their ill siblings. The present study's findings also showed cases of academic failure and even school dropout. The healthy siblings also felt uncomfortable because they were asked questions about their ill siblings' condition by their teachers and peers (22). According to the participants' statements regarding the category of “loss of normality” in the theme of “change of life,” Kaatsiz et al. considered the change in family routine as an influential factor in school life, caused by concern for one's ill sibling's condition; this causes difficulty in concentrating on studies (21). This is more serious in those aged between 16 and 17 who are preparing for the university entrance exam and are worried about the future. However, Løkkeberg et al. described school attendance as a natural activity in the dimension of “helpful resources for coping.” The fatigue caused by school attendance and related activities makes the healthy siblings' minds less focused on their sibling's illnesses (17).

The theme of "effort to improve the situation" in this study refers to adapting to the situation and keeping a balanced life. People's coping styles depend on their age and personality traits and the severity of their siblings' condition. Some participants turned to spirituality to deal with this suffering. Løkkeberg placed "praying to god" in the category of "faith and hope" and the dimension of "helpful resources to cope" (17). This was in line with the "spiritual adaptations" subcategory in the present study.

Participants in that study focused on existential issues such as hope, life, death, and identity. Adolescent siblings of children with cancer may have different experiences. However, this may be the first time they have been concerned about such questions. In adolescence, the ability for abstract thinking increases, and the ability to relate to these questions depends on how developed the adolescent is.

Age-appropriate social and professional support can help siblings think about existential questions (17). Packman reported "instillation of hope" (24), and Kaatsız reported, "spiritual coping" in the theme of "coping styles" (21). Those who see signs of improvement focus more on the positive aspects of traumatic experiences. However, the most common coping strategy is "avoidance" (17, 25). Long et al. reported that a change in a family's life routine and a decline in the family's attention force children to face their problems alone (26). Some of the participants spent time with friends or other loved ones. The participants in the study conducted by Løkkeberg et al. also mentioned sharing feelings, avoidance, spiritual coping, and engaging in sports, music, and painting as coping styles (17), and the subcategory of "paying attention to leisure time" was mentioned in the category of "an effort to keep a balanced life" in the present study. The study results conducted by Havill et al. also showed adaptation patterns in the form of changes in personal and familial life and efficient management of the situation (18).

The third theme was "psycho-emotional function," which included two subcategories of "emotions" and "range of feelings." Siblings of children with cancer often feel sad and angry and, therefore, experience emotional pressures from witnessing the disease and observing the physical changes in their siblings. They see the physical changes in their ill sibling's face and hair and their thinness, mood changes, pain, and sadness due to being attached to medical equipment and medications' side effects. This creates unpleasant feelings, which were clearly stated in the present study results. Another issue is the feeling of loneliness and parents' lack of attention, which is less prominent in adolescents older than 15 since they understand the situation. If this understanding does not exist, they will be overwhelmed with anger. They are angry about the disease and its complications and express their anger to their parents or friends. They are afraid of losing their siblings, and they may be in shock of facing this situation and might not believe this has happened to them. Providing social support can improve stress management in them. Prchal et al. reported "worry and fears" and "jealousy" in the dimension of "ill child" (22). Løkkeberg et al. Placed "fear" and "loneliness" as separate categories in the dimension of "cancer into life" (17). However, in the study conducted by Kaatsız et al., "cancer is a scary, bad thing," and "emotional strains" were in the category of "first encounter with the disease."

The fourth theme was "family function," which included two categories of "instability in the family" and "meeting the needs." In line with the results of the present study, Løkkeberg, in the category of "cancer into life" and the dimension of "new routines and concerns," stated that adolescents who have siblings with cancer are separated from their parents. In the first months after the diagnosis, other family members are at the hospital, and healthy siblings experience physical detachment from parents due to the ill child's hospitalization. During this time, the family's main focus is diverted from usual things toward the disease and treatment; this is affected by both the ill child and other family members' conditions. Even when other family members are at home, healthy siblings must be more careful and cannot behave as they did before. Factors, such as the risk of infection, force the siblings to always be quiet and careful, which can be tiring (17). Prchal et al. reported "absence of parents" and "restrictions on holidays" in the dimension of "family life." Most siblings felt lonely and did not like the empty house. Parents were not available for important things such as helping the healthy siblings do their homework, listening to what was going on in their lives, and having meals. Holidays planned before the diagnosis had to be canceled, or the siblings had to spend the holiday with their relatives (22). "Loss of normality" is also a subcategory of "change in life." According to the participants, unlike the common belief that mothers do the housework, fathers helped with the housework more often (21).

The last theme extracted from the interviews was "individual health," which included two categories of "signs and symptoms" and "general health" affecting the QoL of siblings of children with cancer. This issue was not mentioned in other studies. It seems that physical problems are temporary and observed soon after diagnosis or when the child is tired due to constant care. Psychological health is more important than physical health from the point of view of these participants.

Strengths and limitations of the study

The present study is the first study exploring the experiences of QoL in siblings of children with cancer in Iran. Nonetheless, the selection of the adolescents in the present study was due to their personal, social, developmental and emotional characteristics, specific to the teenager group and these results cannot be generalized to other children in other age groups. They should be also generalized to other societies with caution. Another limitation of the study was the COVID-19 pandemic at the time of the study. Therefore, there was online education in schools and it can influence relations among peers and also study results.

Conclusions

The present study was the first study allowing the siblings of children with cancer to share their QoL experiences. Based on the participants' experiences, five dimensions of QoL were extracted for siblings of children with cancer, including "individual function", "effort to improve the situation", "psycho-emotional function", "family function" and "individual health".

Siblings of children with cancer reported difficulty adapting to the new family roles and routines and often used several coping strategies. Thus, healthcare providers are expected to support them by planning intervention programs. It is important that they can share their feelings and experiences, to get

the social support of peers with similar experiences and professional psycho-social support and interventions. Healthcare providers should support parents to understand the needs of their healthy children in the family and informing them of how to support family members. These strategies can improve the QoL in siblings of children with cancer and reduce their stress during the challenging time.

Declarations

Ethics approval and consent to participate

This research was performed in accordance with the Declaration of Helsinki and methodology was approved by an ethics committee with ethical number 1129.1397.REC.RETECH.SBMU.IR at the University of Shahid Beheshti. All participants provided written, signed consent to their involvement. So the researchers was obtained written informed consent from parents of adolescents , as well as parents and nurses for study participation.

Consent for publication

Not applicable.

Availability of data and materials

The data from the qualitative interviews are not publicly available to maintain confidentiality of centres and individuals, as per ethical approval. However, all reasonable requests for information will be provided on request to the corresponding author.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

All authors designed the study, wrote the interview guide and the first draft. MM performed the interviews and did transcription of the interviews and analysis. All authors participated in data analysis and checked accuracy of the data and revised different versions of the manuscript. The authors read and approved the final manuscript.

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References

1. Hockenberry MJ, Wilson D. Wong's nursing care of infants and children-E-book. 11, editor: Elsevier Health Sciences; 2018.
2. Kenney K. Social support and health-related quality of life among healthy middle-childhood aged siblings of chronically ill children: Teachers College, Columbia University; 2010.
3. Limbers CA, Skipper S. Health-related quality of life measurement in siblings of children with physical chronic illness: A systematic review. *Families, Systems, & Health*. 2014;32(4):408.
4. Fleary SA, Heffer RW. Impact of growing up with a chronically ill sibling on well siblings' late adolescent functioning. *ISRN family medicine*. 2013;2013.
5. Velleman S, Collin SM, Beasant L, Crawley E. Psychological wellbeing and quality-of-life among siblings of paediatric CFS/ME patients: a mixed-methods study. *Clinical child psychology and psychiatry*. 2016;21(4):618–33.
6. Gan LL, Lum A, Wakefield CE, Nandakumar B, Fardell JE. School Experiences of Siblings of Children with Chronic Illness: A Systematic Literature Review. *Journal of pediatric nursing*. 2017;33:23–32.
7. Barrera M, Atenafu E, Nathan PC, Schulte F, Hancock K. Depression and quality of life in siblings of children with cancer after group intervention participation: A randomized control trial. *Journal of pediatric psychology*. 2018.
8. Group W. The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Social science & medicine*. 1995;41(10):1403–9.
9. Khaledi S, Moridi G, Valiee S. Comparison the quality of life of healthy and Thalassemic children. *nursing research*. 2013;8(29):87–94.
10. Defenderfer EK, Rybak TM, Davies WH, Berlin KS. Predicting parent health-related quality of life: evaluating conceptual models. *Quality of Life Research*. 2017;26(6):1405–15.
11. Padmaja G, Vanlalhruii C, Rana S, Kopparty S. Quality of life of patients with cancer: a determinant of the quality of life of their family caregivers. *Journal of cancer education*. 2017;32(3):655–61.
12. Kumagai N, Hatta M, Okuhara Y, Origasa H. Validation of general linear modeling for identifying factors associated with Quality of Life: A comparison with structural equation modeling. *Health*. 2013;2013.
13. Serinkan C, Kaymakçı K. Defining the quality of life levels of the nurses: a study in Pamukkale University. *Procedia-Social and Behavioral Sciences*. 2013;89:580–4.
14. who.int/tools/whoqol.
15. Fulton JS, Miller WR, Otte JL. A systematic review of analyses of the concept of quality of life in nursing: exploring how form of analysis affects understanding. *Advances in Nursing Science*. 2012;35(2):E1-E12.

16. MR R, H M. Measuring quality of life: Review of concepts, indicators, models and proposed model for rural areas *Rural Development Journal*. 2008;11(3):1–26.
17. Løkkeberg B, Sollesnes R, Hestvik J, Langeland E. Adolescent siblings of children with cancer: a qualitative study from a salutogenic health promotion perspective. *International Journal of Qualitative Studies on Health and Well-being*. 2020;15(1):1842015.
18. Havill N, Fleming LK, Knafl K. Well siblings of children with chronic illness: A synthesis research study. *Research in nursing & health*. 2019;42(5):334–48.
19. Fullerton JM, Totsika V, Hain R, Hastings RP. Siblings of children with life-limiting conditions: psychological adjustment and sibling relationships. *Child: care, health and development*. 2017;43(3):393–400.
20. Yilmaz O, Turkeli A, Karaca O, Yuksel H. Does having an asthmatic sibling affect the quality of life in children? *The Turkish journal of pediatrics*. 2017;59(3):274–80.
21. Mendes TN, Sá RF, Araújo YB, dos Santos SR, Nascimento JA, Costa CM, et al. Socioeconomic and Demographic Profile of Children and Adolescents with Chronic Disease: Integrative Literature Review. *International Archives of Medicine*. 2016;9.
22. O'Brien I, Duffy A, Nicholl H. Impact of childhood chronic illnesses on siblings: a literature review. *British Journal of Nursing*. 2009;18(22):1358–65.
23. Erker C, Yan K, Zhang L, Bingen K, Flynn KE, Panepinto J. Impact of pediatric cancer on family relationships. *Cancer medicine*. 2018;7(5):1680–8.
24. Bakas T, McLennon SM, Carpenter JS, Buelow JM, Otte JL, Hanna KM, et al. Systematic review of health-related quality of life models. *Health and quality of life outcomes*. 2012;10(1):134.
25. Sousa KH, Kwok O-M. Putting Wilson and Cleary to the test: analysis of a HRQOL conceptual model using structural equation modeling. *Quality of Life Research*. 2006;15(4):725–37.
26. Villalonga-Olives E, Kawachi I, Almansa J, Witte C, Lange B, Kiese-Himmel C, et al. Pediatric health-related quality of life: a structural equation modeling approach. *PloS one*. 2014;9(11):e113166.
27. Zubritsky C, Abbott KM, Hirschman KB, Bowles KH, Foust JB, Naylor MD. Health-related quality of life: Expanding a conceptual framework to include older adults who receive long-term services and supports. *The Gerontologist*. 2012;53(2):205–10.
28. Nikrouz L, Alhani F, Ebadi A, Kazemnejad A. The concept of self-control in the family caregivers of patients with chronic disease based on the family-centered empowerment model: A qualitative directed content analysis. *HAYAT*. 2020;26(2):218–37.
29. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today*. 2004;24(2):105–12.
30. Kaatsız MAA, Öz F. I'm Here, Too: Being an Adolescent Sibling of a Pediatric Cancer Patient in Turkey. *Journal of pediatric nursing*. 2020;51:e77-e84.
31. Prchal A, Landolt MA. How siblings of pediatric cancer patients experience the first time after diagnosis: a qualitative study. *Cancer nursing*. 2012;35(2):133–40.

32. Toft T, Alfonsson S, Hovén E, Carlsson T. Feeling excluded and not having anyone to talk to: Qualitative study of interpersonal relationships following a cancer diagnosis in a sibling. *European Journal of Oncology Nursing*. 2019;42:76–81.
33. Packman W, Greenhalgh J, Chesterman B, Shaffer T, Fine J, VanZutphen K, et al. Siblings of pediatric cancer patients: the quantitative and qualitative nature of quality of life. *Journal of Psychosocial Oncology*. 2005;23(1):87–108.
34. Long KA, Marsland AL, Wright A, Hinds P. Creating a tenuous balance: Siblings' experience of a brother's or sister's childhood cancer diagnosis. *Journal of Pediatric Oncology Nursing*. 2015;32(1):21–31.
35. Long KA, Pariseau EM, Muriel AC, Chu A, Kazak AE, Leon M, et al. Psychosocial screening for siblings of children with cancer: Barriers and preferences. *Clinical Practice in Pediatric Psychology*. 2017;5(4):364.