

Experience of Adolescent Survivors of Childhood Cancer about Self-Care Needs: A Content Analysis

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ABSTRACT

Objective: In cancer care management, patients or their family are usually responsible for continuing health care. Achieving this goal requires identification of their self-care needs. The purpose of this study is to explore the perception of self-care needs of adolescent cancer survivors. **Methods:** This study was conducted by the qualitative content analysis method. Participants were 19 adolescent childhood cancer survivors and six parents, nurses, physicians, and charity institution staff from children teaching hospitals in Iran. Participants were selected through purposeful sampling, and individual semistructured interviews were used for data collection. Graneheim and Lundman stages of content analysis were employed for data analysis. Data were managed with the MAXQDA10 software. **Results:** Content analysis revealed nine subcategories as follows: (1) nutritional protection, (2) prevention from infection, (3) prevention from physical damage, (4) control over cancer recurrence, (5) informational

needs, (6) pain management, (7) releasing positive thoughts, (8) continuing routine life, and (9) family protection. The first six subthemes were related to protection against physical distress, and the final three ones were related to protection against psychological distress. These two categories form one theme: “protective self-care need” as an essential self-care need in adolescent cancer survivors. **Conclusions:** Pediatric and school health nurses can prepare strategies to meet these needs by providing effective informational and psychosocial supports, and healthcare providers are able to check periodically the status of survivors care to provide second or third level of care to prevent escalation and incidence of the adverse outcomes of the disease.

Key words: Adolescent, cancer survivor, childhood cancer, need, protection, qualitative study, self-care

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Introduction

Developments in controlling chronic diseases have led to attention toward childhood cancer^[1] so that the approximate 5-year survival rate for childhood cancer has increased up to 80% in the developed countries.^[2] Consequently, the support and attention to needs of cancer survivor such as medical follow-up, late effects, chronic disabilities, and psychosocial problems as well as other long-term problems have been increased.^[3] In chronic diseases, patients or their families are usually responsible for continuing care and achieving this goal requires a comprehensive view to care provision, especially self-care needs.^[4] Inappropriate cancer self-management increases the negative effects on the patients' quality of life.^[5]

Self-care needs are those whose meeting them requires a specific level of activities, services or support in orders to provide the desired welfare.^[6] According to Orem's opinion on the self-care need, three importance needs create when the health is violated and the disease breaks out. These needs include: (1) the needs related to the patient's physical changes, (2) the needs related to the individual's performance, and (3) the needs related to the changes in behavior.^[7]

Identifying patients' needs is one of the primary steps of the nursing process to plan and implement nursing interventions and prevent late effects.^[8] In a systematic review, information about the treatment, side effects, and cancer recurrence was the most important self-care needs among the cancer survivors.^[3] Attention to survivors' psychosocial needs and their quality of life is important and forms an essential part of modern nursing care.^[9] However, there is little information about the self-care needs of survivors and the way these needs affect their lives. Only some limited surveys are conducted on childhood cancer survivors' satisfaction that stressed on the importance of a good perceived health professional-patient relationship.^[10] Childhood cancer treatment affects all physical, psychosocial, economical, and existential aspects of the survivors' lives.^[11] It is believed that self-care needs are influenced by the patient's age, gender, developmental stage, experience, and sociocultural background.^[12] Adolescence is one of the most important and a crucial period of all individuals' life, and passing it successfully guarantees a healthier future.^[13] According to the definition of World Health Organization, adolescence refers to age group between 10 and 19 years.^[14] Self-care in adolescents is considered as a useful activity to promote health of society.^[13]

Healthcare providers are faced with challenges in the vast self-care needs of survivors,^[15] and reviews in this area are usually unsystematic and focus more on specific

problems.^[16] The absence of a national protocol to control cancer care along with the fragmented health care system is the most important problem in caring for cancer survivors in Iran. Therefore, many cancer survivors miss the opportunity of early diagnosis for late effects and treatment because of poor knowledge and low accessibility to healthcare system.^[17]

Lack of satisfaction from care services, different ability of professionals to provide relevant information, and the inability or reluctance of survivors to choose their own care, anxiety, and concerns have all led to poor documentation of needs.^[16] To find out flexible survival care models for cancer survivors, it is necessary to document the perception of cancer survivors' about self-care needs.^[18]

Considering the importance of evaluating and identifying self-care needs of adolescent cancer survivors, cultural differences in self-care needs, and inadequate documents about patients' experiences of this issue,^[19] this study was conducted to explore perception of adolescent cancer survivors self-care needs.

Methods

Design and sample

This study was conducted by the qualitative content analysis method in Iran. Qualitative research aims to explore and understand the inner world of people; researchers understand the meaning of phenomena in detail by entering into the world of individuals' experiences.^[20] Therefore, the study was conducted following the consolidated criteria for reporting qualitative research.^[21]

Participants were 19 adolescent cancer survivors, and 6 parents, nurses, physicians, and charity institution staff from Children Teaching Hospitals in Tabriz city of Iran that were selected through purposeful sampling until data saturation occurred. Inclusion criteria were 11–19-year-old adolescents, no history of any physical or mental disease except cancer, adolescents who were aware of their disease, and at least 1 year had passed from their last treatment. Exclusion criteria for adolescent include cancer recurrence and mortality in during the research. Because parents are involved in caring for adolescent cancer survivors, most of the adolescents interact with doctor, nurse, and charity staff during treatment and posttreatment of cancer, and they play a valuable role in providing support to survivors;^[22] therefore, parents of adolescent cancer survivors, oncology nurses, oncology physicians, and charity institute staffs were included in the study. The inclusion criteria for parents and healthcare professional included parents of an adolescent survivors of childhood cancer under the age of 19 years; in the family, there should be only one child with cancer survivor and the other family members must be healthy.

Also, health care professional has at least 1 year experience of caring for adolescent survivors of childhood cancer.

Data collection

Data collection was conducted through individual face-to-face interviews. Each interview lasted about 40–55 min. Informed consent was obtained at the beginning of each interview. An interview guide helped to ensure that all the issues were asked. First, participants' demographic information was collected and then interviewer asked the participants "how do you spend your days since your disease have been cured", "what experiences do you have about self-care after treatment?," and "What problems did you face considering self-care after treatment?". The physician, nurse, parents, and the charity center staff were asked the following questions: "what is your perception of self-care in adolescent childhood cancer survivors?" and "what are cancer survivors' main self-care needs and priorities?" In addition, based on the responses and data analysis, explorative questions such as "explain it more to me," and "what does it mean?" were asked. All interviews were recorded by the MP3 voice recorder. In case the participants refused to have their voice recorded, notes were taken from their conversations (one nurse). One participant (participant 9) was interviewed twice to clarify the ambiguous points in her statements.

Sampling and interviews continued until the data saturation was achieved. Saturation occurs when no new data are obtained from the following interviews and the data are the repetition of what was previously collected.^[23] In the present study, according to the research team, after conducting 16 interviews with adolescents, data saturation was achieved and to ensure that no new data would be obtained; three more interviews were conducted with adolescents. Interviews were conducted with prior arrangements with the adolescents and their parents in hospitals. Interviews with the nurses, physicians, and charity institute staffs were conducted in their workplace with prior arrangements. The data collection lasted for 6 months, and the whole research was conducted from February 2017 to February 2018.

Ethical approval

The Human Research Ethics Committee approved the present study. Before starting the interviews, the purpose of the study was explained to participants, and their informed consent was taken to participate (including audio recording). Participants were assured that their recorded voice would be used anonymously. Moreover, participants were given the right to withdraw from the study any time.

Statistical analysis

Data analysis was done using a conventional content analysis method. In this method, the researcher does not

use previous theories or studies to do primary coding. As the data analysis proceeds, initial coding is planned, reviewed, and modified.^[20]

To implement conventional content analysis, Graneheim and Lundman's proposed five steps were used. These steps included: (1) transcribing the entire interview immediately after each interview, (2) reading the whole text for comprehensive understand of its contents; (3) identify the meaning units and primary codes; (4) classifying similar primary codes in more condensed units and comprehensive categories; and (5) modifying the primary categories by research team; and (6) revealing the implicit meaning and hidden content of categories.^[24] Similarly, in this study, the data were analyzed following these steps. To verify the coding method, two PhD researchers in the field of nursing check the codes and verified them. To confirm the reliability, the Cohen Kappa coefficient formula was used. Kappa coefficient was used to verify percent agreement across evaluators. In this study, the agreement between the two evaluators was 0.74, which represents 74% of the agreement between them. MAXQDA software 10.0R250412 (developed and distributed by VERBI Software Company in Berlin, Germany) was used to manage of data.

Trustworthiness means the assurance degree about data accurateness.^[25] To achieve the trustworthiness, the methods proposed by Lincoln and Guba (credibility, confirmability, dependability and transferability) were used.^[26] Credibility of the data was assessed by researcher long-term engagement with data, indirectly participants' perspectives during the research, transcribing interviews instantly and reviewing the interview with participants to confirm the accuracy of transcriptions compared to what they had stated. Conformability of data means the data coding is stable and reliable in identical time and condition;^[25] to achieve this goal, two external PhD supervisors with research experiences in qualitative study evaluated the interviews, primary coding and the categories. To ensure dependability, the raw data, codes and categories were kept for audit purposes, and all procedures of the study and details were noted and recorded. For transferability, the sampling with maximum diversity was used.

Results

The 25 eligible participants included 19 adolescent cancer survivors, 2 parents, 2 nurses, 1 physician, and 1 staff from cancer charity center. The mean current age of adolescents were 15 (standard deviation [SD] = 2.51) years, 57.89% of the adolescents were female, the mean age at cancer diagnosis was 7.89 (SD = 3.78) years, the mean length of treatment was 2.60 (SD = 0.95) and the mean length of off

therapy was 4.39 (SD = 2.95) years [Table 1]. The number of new subcategories in each interview has been shown in Table 2. Nine subcategories and two categories were derived from content analysis [Table 3].

Protection from physical distress

One point that was repeated in most participants' statements was the need to be protected from physical distress. This need had different types such as nutritional protection, protection against infection and physical damage, control over disease recurrence, searching information, and pain control. Each subcategory is explained as follows:

Nutritional protection

For childhood cancer survivors, it was a need to prevent nutritional risk factors through observing healthy nutritional patterns and avoiding unhealthy diet. One of the survivors said:

I should not use processed foods and eat fruits and vegetables that are organic, but many of the foodstuffs that we use are hormonal. Finding the local type of these foods is difficult for my parents, nobody informed us about how to get them and if we find them, sometimes their prices are so high that my family cannot afford it (P7).

Prevention from infection

Most of the survivors stated that the potential for infection in them is high. Survivors protect themselves from infection through personal hygiene, not eating the old foods,

and getting cautiously for going crowded places. One of the cancer survivors said:

Even though take care of my health, I always get sick more than my classmates, especially in the cold season, I am usually absent in school because of frequent colds or I have to be away from my classmates and definitely use mask (P8).

Prevention from physical damage

Cancer causes the body to suffer from fatigue and therefore, most of the survivors have begun physical activity slowly to prevent physical damage. One of the adolescents' fathers whose son was osteosarcoma survivor said:

My son staggers because of his illness; he does not play football and volleyball much at school to protect his legs. Therefore, his physical education coach takes care of him not to be hurt (P20).

Control over cancer recurrence

Adolescent cancer survivor needed continuous clinical and laboratory examinations; follow up care and treatment of various complications of body systems to control the threat of recurrence. One of the nurses said:

Most of the survivors are worried about the possibility of returning the disease; therefore, they come for frequent follow-up visits and do some diagnostic tests, for example, CBC, ESR, and lung CT or MRI to control the recurrence (P21).

Informational needs

Participants search for information in various ways, some of the information was obtained through their surviving counterparts, and others had careful attention to clinical

Table 1: Self-explanatory data of adolescent

Gender	Current age of adolescent (years)	Age at diagnosis (years)	Diagnosis	Treatment	Off therapy period
Male	12	6	Leukemia	3	3
Female	16	13	Leukemia	2	1
Male	14	10	Osteosarcoma	2.5	1.5
Female	13	9	Hodgkin's lymphoma	2	2
Male	19	8	Ewing sarcoma	2	6
Male	15	7	Leukemia	3	5
Male	17	15	Hodgkin's lymphoma	1	1
Female	19	14	Leukemia	1	4
Female	14	10	lymphoma	3	1
Female	12	5	Leukemia	4	3
Male	11	5	Wilms tumor	3	4
Female	16	3	Wilms tumor	5	8
Male	17	12	Osteosarcoma	2	3
Female	12	3	Brain tumor	3	6
Male	14	10	Osteosarcoma	2	2
Female	18	4	Leukemia	3	11
Female	13	3	Retinoblastoma	2	8
Female	18	6	Rhabdomyosarcoma	3	9
Female	15	7	Leukemia	3	5
Male = 42.1%	Mean ± SD	Mean ± SD	-		Mean ± SD
Female = 57.89%	15.0 ± 2.5	7.9 ± 3.8	-		4.4 ± 3.0

SD: Standard deviation

Table 2: Frequencies of statements referring to a subcategory

Subcategories	Number of participants																			Total events	
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19		
Nutritional protection	*	*	*	*	*		*			*		*	*			*			*		11
Prevention from infection	*	*	*					*	*		*	*				*					8
Prevention from physical damage	*	*			*			*	*					*							6
Control over cancer recurrence	*	*	*	*	*	*	*			*	*	*	*		*		*	*	*		15
Informational need		*		*	*				*		*		*	*			*		*		9
Pain management			*			*			*				*	*				*		*	6
Releasing positive thoughts				*	*				*	*		*			*		*		*		8
Continuing routine life						*		*					*			*		*		*	5
Family protection								*				*	*			*		*		*	5
Occurrence of subcategories	4	5	4	4	5	3	2	4	5	3	3	5	6	3	3	3	3	4	4		73
Total new subcategory in each interview	4	1	1	2	1	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0

*Occurrence of subcategory in participant

Table 3: Finding of content analysis

Theme	Category	Subcategory
Protective self-care need	Protection against physical distress	Nutritional protection
		Prevention from infection
		Prevention from physical damage
		Control over cancer recurrence
		Informational needs
	Protection against psychological distress	Pain management
		Releasing positive thoughts
		Continuing routine life
		Family protection

symptoms and asked the physician or nurse. One of the survivors told:

Neither the doctors nor the nurses gave us nutritional or educational consultation about receive care at home. When we refer to the clinic and show the tests, doctor says: "it's ok." Then he examines me, but he doesn't explain the tests or medicines. I and my parents got some experiences and also asked others for some information; for example, what activities I can do, what foods are good for me or what are the symptoms of disease recurrence (P5).

Pain management

Some of the survivors suffered from chronic pain. Of course, because of less pain, most of them use nonpharmacological pain relief methods, as one of the adolescents said:

After the treatment ended, my pains decreased but they never disappeared. Sometimes that I do more activities, they get worse. Therefore, I need to take a rest and not to think about my pain (P18).

Protection from psychological distress

Most of participants stated that there are psychological effects of cancer even after treatment has stopped. Therefore, some cancer survivors have been using psychological approaches to protect themselves from the distress. This heading includes three subthemes.

Releasing positive thoughts

Most of the cancer survivors need to protect them from mental distress; therefore, they try to get away from negative thoughts about their illness and focus on other things. They used different approaches such as positive thinking, optimism to the outcome of treatment, connect with friends and travel, read books, concentrate their mind and do yoga, or attend in happy and entertaining environments and religious care. One of the survivors said:

I'm always upset when my family or other people talking about my disease. I do not want to remember the hard days of treatment or think about my illness. I may take a trip with my friends, or communicate with friends who have more optimistic point of view towards life (P17).

Continuing routine life

A number of survivors partially adapted themselves to the illness and conditions and tried to continue their normal routine life. The mother of one of the adolescent said:

At school, my daughter's chair is separated from the rest of her classmates. Is such high sensitivity necessary towards these children? I tried to treat her as a normal person. For example, I asked her to clean up her clothes and room because doing her own tasks her a normal person (P21).

Family protection

The cancer survivors said they caused the family's discomfort for their illness, so they avoid expressing their feelings to their family, to prevent the adverse effects of disease and problems to affect the mental health of their family. One of the survivors said:

My family is always anxious about my coughs. They count them, they ask me why I'm coughing more today! My parents' sadness makes me sad too, so I sometimes hide my physical symptoms, just not to make them worried (P5).

Discussion

This study was carried out with the aim of identifying adolescent cancer survivors' self-care needs. Based on the participants' point of view, protective self-care was their main need after recovering from cancer treatments. Participants try to hinder cancer recurrence through taking care of and protecting themselves against risky factors. Protection is considered as a behavior to prevent potentially harmful incidents such as illness to reduce the negative outcomes of disease.^[27] Protection creates a line of defense against the invading disease that strengthens and improves one's adaptability. In this regard, the North American Nursing Diagnosis Association, a professional organization of nurses interested in standardized criteria and taxonomy of nursing diagnoses, explains that ineffective protection is "reducing the ability of individual to cope with internal and external threats," and it has put this term in the health promotion and control class.^[28] In a qualitative study, one of the themes found in the results was "protective aspect". This theme indicated patients' perspective on self-care as a protection for themselves, their family, and community against diabetes.^[29] Therefore, it is necessary for cancer survivors to adopt protective policies against cancer risk factors to prevent adverse complications.

One of the findings of this study was the protective needs against nutritional risk factors. The results of studies showed that the level of knowledge about risky nutritional behaviors was low, and from the participants' point of view, one of the most important needs of society was structural programs and educations about healthy nutrition.^[30,31] Receiving sufficient amount of certain nutrients and supplements is associated with the prevention of cancer recurrence.^[30] Of course, in the present study, in addition to need to be aware of healthy diet, participants were having trouble in getting healthy foods and prices for this type of foods were high. Accordingly, social support, socioeconomic status and cultural ideas affect the selection of healthy food.^[31] Therefore, nutritional education and financial support by the government is required to prevent harmful food consumption.

Infection and physical damage prevention were important for participants. Findings of a prospective longitudinal (Cohort) study about infection in childhood cancer survivors showed that the risk of infection in sinuses, respiratory, digestive and urinary systems of these children are high and it increases their mortality during the follow-up period.^[32] As a result, a need for screening and following-up the medical care after ending the treatment is vital to prevent infection in childhood cancer survivors.^[18] In addition, as a result of the numerous late adverse events related to pediatric cancer treatment, an interest in using exercise

as a therapeutic measure to attenuate or reverse many cancer-related late adverse events in the pediatric population has surfaced.^[33-35] Increasing the amount of physical activities decreases the risk of cancer recurrence and enhances the probability of successful treatment. However, activities that impose too much burden on the patient should be prevented. Since cancer causes muscle atrophy, physical activities in childhood cancer survivors should be started gradually to prevent physical damages.^[35] In present study, despite the importance of exercise in survivors' health, participants did these actions with caution, and activity was different depending on the type of cancer. According to participants' experiences, brain tumor and osteosarcoma survivors due to difficulty in moving the legs and leukemia survivors due to fatigue have done less sporting activities. In order to have a healthy life after treatment, physical activity guidelines about the amount of activity, walking, and exercise are helpful for cancer survivors.^[34]

A need to control cancer recurrence was one of the findings of the present study. In a systematic review that was carried out on the effect of long-term follow-ups on the child cancer survivors, patients were worried about the disease recurrence and its long-term effects, and they referred to their doctors for regular clinical examinations and laboratory experiments to prevent cancer recurrence or secondary cancers.^[36] Follow-up care after completing the treatment helps the individuals and their families in making plans, changing life style, and making important decisions.^[37]

Another finding of this study was the need for information about the disease. This result is according to a research on childhood cancer survivors and their family. Most of the participants had a feeling of uncertainty about treatment and followed various informative behaviors to manage this feeling.^[38] Participants claimed that sometimes they asked their questions from their doctor or caregiver, or used internet and supportive groups to obtain information. Information sharing between childhood cancer survivors may promote positive health care engagement, therefore, there is a need for educating and providing information about self-care during survival period.^[38] Various support services are required to meet the cancer survivor's information needs. These services may be provided in different forms, such as in-person counseling sessions, educational services, or informational resource centers.^[39]

The need for pain management was another finding. In a qualitative systematic review of pain in cancer survivors, the results showed that nonmedical interventions such as physiotherapy, physical exercises, heat and cold massage, electrical skin nerves stimulation, acupuncture, and cognitive behavior therapy are often considered for relieving

chronic pains of cancer survivors.^[40] The participants in present study experienced chronic pain intensified by doing excessive daily activities. Therefore, for better pain management, survivors use different nonpharmacological pain relief methods.

According to the results of this study, releasing positive thoughts was another finding. In a qualitative study on cancer survivors, strategies to reduce psychological distress included making relationships, searching self-care patterns, following up cares, entertainment, quitting bad behaviors, improving and creating positive traits.^[41] Similarly, a study about the effect of writing on emotional relief among the cancer patients showed that writing about feelings caused noticeable improvements in their mental health.^[42] Most of the patients mentioned asking God's help to improve mental health.^[43,44] In fact, these findings suggested that instead of emphasizing the harmful aspects of disease, focusing on the positive and developing aspects is cost-effective and noninvasive. It can be said that the methods used by the participants in this study are coping strategies, which is used to drive out distracting thoughts and negative feelings.

Participants in the current study need to continue their routine life after treatment. In a qualitative study participants claimed that spending the difficult period of treatment let them discover a new meaning for life and they considered the period after treatment as an opportunity to care themselves and follow a normal and healthier life.^[45] Survivors in the present study wanted to do their tasks after their rehabilitation. Therefore, they wanted others to behave them like normal people in the community.

Adolescents wanted to avoid the effect of disease on family. Who believed that the survivors not only took care of themselves, but also cared about others and they are easily empathized with others. Findings of this study are along with the results of Koutná *et al.*, that childhood cancer survivors attempt to or want to avoid cancer-related discussions or situations to prevent the psychological effects on their family.^[46] The results of the present study indicate that protection for family mental distress appeared mostly in older adolescents, who could recognize the psychological burden in their families.

Advantages and limitations

This study has some limitations that need to be considered when interpreting the findings. First, qualitative data is a result of the experience and views of the participants, but since the researcher is as a data collection tool, findings may be influenced by the values of the researcher. To overcome this limitation, a variety of methods such as researcher-prolonged engagement, persistent observation, peer debriefing, and member check (the report or a portion

of transcribed interview is given to members of the sample to check the authenticity of the interview) were used.

Second, due to the qualitative nature of the present study, the number of participants was completed when the data saturation was achieved and categories were shaped. However, the purpose of this study is to understand phenomena deeply, and in detail, therefore, qualitative methods in this research provide valuable data for discovery of central themes and analysis of core concerns and needs of adolescent survivors of childhood cancer.

The strengths of this study were variation in adolescent age range, type of cancer, and sample diversity, which contributes to richness of data.

Implication for research and practice

The findings of this study showed that survivors have protective needs in the area of physical and psychological impairments. Healthcare providers, especially school health nurses, can prepare strategies to meet these needs by providing effective supports such as school health services, school nutrition services, social and psychological counseling services, and physical education (exercise) for adolescent cancer survivors. Given that cancer survivors are mostly outpatients and only need hospitalization in the event of a crisis, the need for community nursing services in this area is felt more. Community health nursing are able to visit periodically the status of survivors (problems, concerns and needs), to provide the required information and second or third level of care to prevent the escalation and incidence of adverse events of the disease. On the other hand, pediatric nurses during the follow-up care sessions in hospitals or clinics can provide mental support and information about self-care during survival period and them to achieve self-care autonomy.

Further studies relating self-care needs can be conducted in younger children and their family. In addition, this study only interviewed with adolescent who were informed about their diagnosis. Further studies could investigate the similarities and differences of self-care in children who were and were not late effects of disease.

Conclusion

The results of this study showed that there is a need to protect survivors from risk factors of cancer through self-care. Effective protection improves survivors' quality of life and self-management. Therefore, strategies and interventions must be used to meet the survivors' needs to contribute to self-care efficacy, personal control, and psychological health of survivors.

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Conflicts of interest

There are no conflicts of interest.

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