Patient Preference and Adherence

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ORIGINAL RESEARCH

Health and Psychosocial Self-Care Needs in Off-Therapy Childhood Cancer: Hybrid Model Concept Analysis

This article was published in the following Dove Press journal:
Patient Preference and Adherence

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Purpose: The self-care concept is a complicated and multi-dimensional phenomenon. There are different opinions about self-care needs; therefore, this study was conducted to clarify the self-care needs of the off-therapy childhood cancer survivors based on the hybrid model.

Patients and Methods: There are three phases in the hybrid model including literature review, fieldwork, and final analysis. At the theoretical phase, 119 articles in databases were evaluated without time limits up to August 2019. At the fieldwork phase, 19 participants were selected with purposive sampling and interviewed through unstructured interviews. Then, the data were analyzed by qualitative content analysis approach. In the final phase, the overall analysis of the two previous phases was carried out and the ultimate definition of self-care needs was presented with the integration of the results of two previous phases.

Results: Theoretical results showed that self-care needs are those that need to be performed by off therapy childhood cancer in everyday life in order to maintain health and well-being through the practice of healthy behaviors and activities. Also, fieldwork results indicated that self-care needs are increased due to the physical, mental, and social vulnerability of the disease. Following that, the need for protective self-care behaviors to prevent against physical and psychosocial side effects arises. If the patients are unable to implement protective behaviors, the need for support from others is created. Therefore, by synthesizing the findings of literature review and fieldwork, self-care needs are two-dimensional concept: (1) need for changing in behavior to protect themselves against physical and psychosocial distress and (2) need for supporting to implement care.

Conclusion: Taking into account the self-care needs, healthcare providers can support childhood cancer survivors in gaining and maintaining independency in self-care. On the other hand, the results of this study by creating a basic knowledge in the field of self-care needs can be used in the development of policy and standards of care to meet the needs of this group.

Keywords: self-care needs, children, adolescents, off therapy, cancer, concept analysis

Introduction

The survival rate of childhood cancer has been increased in recent years, which is the result of development in treatments.[1] The average survival rate of 5 years in childhood cancer has been increased up to 80% in developed countries.[2] Consequently, as the number of off-therapy childhood cancer survivors increases; because of their needs such as medical follow-ups, the side effects of treatment, chronic disabilities, psychosocial problems, and other long-term problems exacerbate.[3,4] As a result, the American Cancer Society believes that to provide

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submit your manuscript | www.dovepress.com
DovePress
http://doi.org/10.2147/PPA.S246558

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desired and high-quality care for these patients, it is required to identify and recognize their care needs.[5] This viewpoint results in the "need" concept in the care of survivors. This concept included the needs, which were not considered previously or meeting them required more support.[6]

Supporting and reinforcing patients' roles, especially in self-care, could lead to better disease-specific clinical outcomes.[7] Identifying patients' needs are one of the first steps in the nursing process to plan and implement health interventions and prevent complications. A comprehensive investigation of the needs helps the healthcare providers and nursing systems to identify the aspects of needs to be met so that they could provide high-quality health care.[8]

Self-care needs in off-therapy childhood cancer survivors are affected by their developmental stages.

Children between 5 and 12 are developing the capacity to think logically and to consider other points of view, including differentiating between themselves and the outside world.[9] Bares and Gelman (2008) compared the beliefs about colds and cancer in children ages 5, 7, and 10. This study illustrates the cognitive developmental progression of knowledge of illness during this period. Results showed that 5-year-old children had similar reasoning about cancer and colds; specifically that they were both contagious illnesses, caused by contact with contaminants, and similar in their length and severity. By age seven, the children began to discriminate between cancer and colds on some of the dimensions, demonstrating an appreciation that cancer is more serious than a cold and lasts longer. At age 10, the children were also able to understand that cancer would not go away on its own and that it was not transmitted through contagion.[10]

In young adult children, adolescence is a start of changes during which the individuals attempt to become independent and create a positive self-concept and relationships. Consequently, facing a disease or its side effects in this period of life is challenging. Autonomy, relationship with peers, and uncertainty about disease recovery or recurrence make the condition more complicated.[11] Childhood cancer survivors could have problems to accept the follow-ups and this difficulty could be worsened in the absence of relationship with the health professionals.[12] Their perceived quality of life could be exacerbated if they underwent Hematopoietic Stem Cell Transplantation compared with their healthy peers.[13]

Despite the well-documented high risk of late arising complications in survivors, up to 77% do not access any regular cancer-specific follow-up care or adhere to their recommended follow-up program.[14] Optimal childhood cancer survivorship care is characterized by high-quality, safe, individualized and risk-based care that is economically feasible and accessible to patients.[15]

Self-care concept is a complicated and multi-dimensional phenomenon. The World Health Organization (2009) similarly defines self-care as: "the ability of individuals, families, and societies to promote health, prevent diseases, maintain health and cope with disabilities and illnesses".[16] Nursing researchers and professionals have some different opinions about the self-care concept. Self-care is associated with some individual factors such as independence, self-efficacy, authority, self-esteem, and individual responsibility and is influenced by socio-economic and political factors.[17] Over the past decades, several approaches have been developed and applied in nursing, each with their philosophical fundaments.[18] This variety in perspectives resulted from the performance, education, experiences, role, and scope of each discipline.[19–22]

Children go through four recognizable stages of development from birth to adulthood that are typically conceptualized as infant, toddler/preschool, school age, and adolescence.[9] In this study, we selected end school-aged children and adolescence that have been off treatment to be able to participate in face-to-face interviews and express their self-care needs. Given the importance of investigating and identifying the problems or needs in health care after cured cancer, the multidimensional aspect of "self-care needs after cured cancer", and cultural differences in the definition of the concept, the present study was carried out to clarify the concept of self-care needs in off-therapy childhood cancer.

Materials and Methods

The hybrid model is one of the methods of conceptualization and theory development. This model consists of three stages including the theoretical, fieldwork, and final analytical stages.[23] This study was conducted according to these stages, to clarify the concept of self-care needs. Each of these three steps is explained below.

Theoretical Stage

The theoretical phase begins with carefully selecting a concept and then examining the available literature related to the concept in other fields.[24] In this stage, review of the literature was conducted with searching all creditable

databases such as Google Scholar, Elsevier, Science Direct, PubMed, Sage, Scopus, Web of Science, ProQuest, and Blackwell using the keywords "concept analysis", "children cancer survivors", "young adult children cancer survivors", "self-care needs", "cancer needs", "survivors care needs", "off-therapy of cancer", "childhood cancer", "hybrid model", and "qualitative study". Next, all the collected qualitative and quantitative studies which had been published up until 2019 which described aspects of self-care needs for cancer survivors were reviewed. The searches were carried out independently by the first and second authors and verified by the third author. In total, 339 articles were identified, 234 through PubMed, 78 through Scopus, 18 from Ovid, 9 through ProQuest. After irrelevant and duplicate papers had been eliminated, 119 abstracts were left, and then unrelated articles, which were issued on general self-care or care for healthy people, were excluded. Ultimately, 35 related articles were identified and used considering the references of this study (Figure 1). All the selected articles were read and re-read for essential elements that are required for definition and measurement of "self-care need after cured cancer". The careful readings shed light on the different aspects of self-care need.

Fieldwork Stage

The qualitative content analysis approach and consolidated criteria for reporting qualitative research (COREQ) were used for this stage.[25] Purposeful sampling was conducted until data saturation occurred. Samples were selected from Children teaching hospitals and Charity institutions of Tabriz, Iran. At last, 19 individuals were included in the study. Regarding the variety, there were 12 off-therapy childhood cancer survivors between 10 and 19 years old, two parents of these children, two oncology nurses, one oncologist, one teacher, and one staff from a cancer charity institution. To collect the data, the individual face-to-face interviews were used. Interviews were implemented in an unstructured manner; however, they were changed to semi-structured interviews gradually after the emergence of categories to collect comprehensive data. This is called a combined approach in an interview. In this approach, an informal conversational interview can be used with a semi-structured interview or a semi-structured can be combined

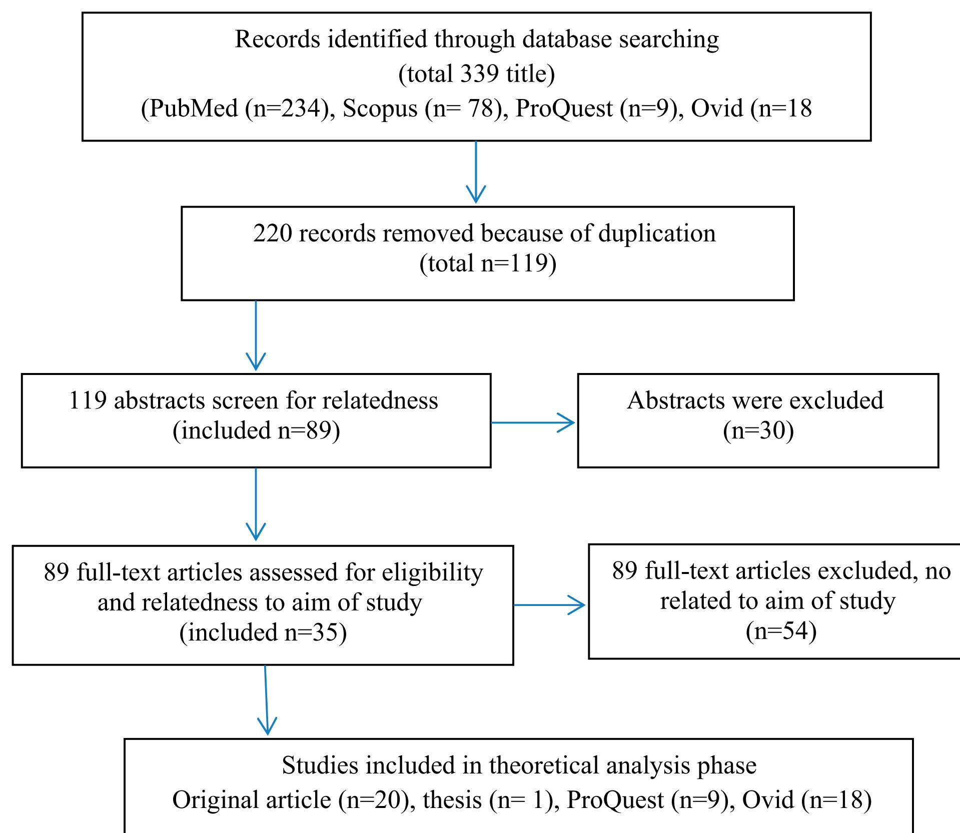

Figure 1 Procedure of literatures identification and selection of articles.

with a standardized interview. This combination strategy gives the interviewer flexibility and can be used on specific topics that require more depth.[26] Sampling and interviews continued until the data saturation was achieved. Saturation is defined as the stage in which by continuing data collection, no new information is obtained and the collected data are repeated.[27] In the present study, according to the research team, after conducting 16 interviews, data saturation was achieved, and to ensure that no new data would be obtained, three more interviews were conducted. The interview guide was used to ensure that all subjects were informed. Interview guide questions can vary based on the interview process and the answers given by the participant.[28] For example, in this study, after the emergence of the "Supportive Self-Care Needs" category, to further complete subcategories details, participants were asked to explain their experience about sources of support that they need to receive for better care. All interviews were done with prior arrangements in the hospitals or the participants' workplace. Before the interviews started, the aim of the study, participation in the interview, and recording their voice were explained to the participants and the informed consent was obtained from them. At the beginning of each interview, the participants' demographic information, cancer history, and the way of getting aware of disease were asked from the participants. Following that, the interview started with general questions of "How do you spend your daily time (24 hours) since your disease has been cured?", "What self-care experiences do you have after treatment?", "What problems in self-care did you have after treatment?" Some questions were asked from the physician, the nurse, families, teacher, and charity institution staff including "What is your perception of self-care in off-therapy childhood cancer?", "What are the most important needs and priorities in off-therapy childhood cancer?" The data analysis was performed using the qualitative content analysis method. The steps proposed by Graneheim and Lundman were used to carry out content analysis.[29] Immediately after each interview, its content was transcribed verbatim and typed. Later, the transcribed statements were read several times and primary codes were extracted. Following that, the codes were combined and sorted based on their similarities. Finally, implicit meaning and concept in the data were extracted. MAXQDA 10 software was used for the management of data. Methods proposed by Lincoln and Guba (credibility, confirmability, dependability, and transferability) were used to promote validity and trustworthiness.[30] To ensure the credibility of the data, long-term engagement with data, indirect participants' perspectives, immediate transcription of interviews, and participants' confirmation on the accuracy of the transcription were used. For confirmability of coding that is stability and reliability of data at a similar time and conditions, two external researchers holding the nursing Ph.D. degree with qualitative research experience were requested to evaluate the interviews, initial coding, and categories until agreement was achieved. In this study, the inter-rater agreement between the two judges was calculated using Holsti method.[31] A coefficient of 0.7 and higher indicates good agreement between coders. For example, the level of agreement with 25 codes (14 codes for the researcher, 11 codes for the other researcher, and 10 common codes) equal to 0.8. According to the minimum coefficient of agreement, the coding method seems appropriate.

To ensure dependability, the raw data, initial codes, and categories were kept for the audit purposes. For transferability, sampling with maximum diversity was used.

Final Analytical Stage

In this phase, the findings of the fieldwork stage were compared with the theoretical stage data,[23] all obtained data were put together to identify their content meaning.[32] According to the research team's opinions, the differences and similarities of the first and second stages were assessed, and concept definition with additional and clear interpretation was extracted. Finally, a refined definition of self-care needs in off-therapy childhood cancer was provided, which is supported by both literature and childhood cancer survivors' perspective.

Ethical Approval

The protocol for this study was approved by the Ethics Committee of Tabriz University Medical Sciences, Iran (approval number: IR.TBZMED.REC.1396.114), and conducted with permission from Children Teaching Hospitals and Charity Institutions administrative authorities under the Helsinki Declaration.[33] Before the interviews started, the purpose of the study was explained to participants and the written consent to participate in the study was taken (including interview and audio recording). Also, a written informed consent for research involvement was obtained from the parent/legal guardian of any participant under the age of 18 years. Participants were assured that their recorded voice would be used

anonymously. Moreover, participants were given the right to withdraw from the study at any time.

Results

Findings of Theoretical Stage

Review of the Concepts and Related Definitions

Definitions of "needs" and "self-care needs" were found in various informative databases and sources. The studies had mainly issued "healthcare needs" and almost none of them had investigated and defined "self-care needs" in cancer survivors. Self-care needs means anyone meeting them requires a specific level of activities services or support to provide the desired welfare.[34]

According to Orem's opinion on the self-care need, three important needs are created 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. Therefore, every individual has some self-care needs that must be met to maintain their health and wellbeing.[35] Self-care is a process through which individuals take their health responsibility, perceive the way to improve it, and identify the things that damage it. The process of health promotion occurs in individuals' daily lives to maintain their life, health, and wellbeing through implementing healthcare behaviors and activities.[35–38] Accordingly, one of the areas obtained in reviewing the concept and definitions of self-care need was "need for changing in behaviors and activities" (Table 1).

Self-care is not only confined to the individual who cares himself but also includes the cares provided by others as well. The care might be provided by the family members or other people until the patient is enabled to take care of himself.[39] Self-care is implemented when an individual is healthy or ill. All individuals implement some levels of daily self-care; however, when they become ill, the priority is to manage the disease and the need for self-care is raised to maintain the health. Therefore, self-care implementation is feasible in both health conditions and when an illness occurs; however, they do not follow a similar process.[36] However, the psychological and sexual self-care will not be considered as well as physical care in cancer survivors. Olsson et al (2019) showed that adolescent and young adult childhood cancer survivors feel less attractive due to scars from the cancer operation. The feeling of attractiveness was negatively related to the size of the scar.[40] Another study showed that cancer survivors had a lower satisfaction concerning sexual function compared to controls. Female cancer survivors had a lower frequency of orgasm during sexual activity than the controls. Male cancer survivors had a lower sexual desire than controls. The lower frequency of orgasm may depend on sensual loss due to the previous chemotherapy in childhood.[41] Therefore, one of the obtained domain in the concept and definitions in the literature review was "supportive care needs" (Table 1).

Review of Related Themes

The available and related databases were reviewed using the following questions: "What are off-therapy childhood cancer problems concerning self-care?", "What are off-therapy childhood cancer self-care needs?", "What strategies do the off-therapy childhood cancer need to implement self-care?". Regarding to these questions, the related themes were extracted from the literature.

After ending the primary treatment, survivors are exposed to a variety of long- and short-term effects of cancer and its treatment. These may include physical problems, undesired quality of life, psychosis, sexual problems; trouble in social relationships, finance-related anxiety, living a life accompanied by uncertainty and fear of disease recur, lack of balance, and self-changes.[57,59] Besides, more than half of the survivors suffer from some restrictions in physical activities and one-third of them have constraints in doing their daily chores[60,61] and fatigue might persist in these patients for years after curing the disease.[62,63] These problems and anxiety result from the unmet needs in these patients.[46]

Literature review on the information-related needs of off-therapy childhood cancer survivors showed that they need information about the treatment and precautions, rehabilitation, future cares for personal and interpersonal health, social and financial adaptation, legal agents, physical and sexual image.[52,53] It should be noted that these needs vary from the moment of the disease recognition to active treatment and end of treatment. During the treatment, the needs are mainly focused on the treatment and its side effects, but then health promotion is important.[51,58,64]

Literature has indicated that most of the off-therapy childhood cancer survivors have at least one unmet need in the first year following the treatment, which includes the need for emotional, social, and religious support, the need for managing the side effects, the need for obtaining the knowledge about dieting, exercising, fertility, and the need

Table 1 Concept Definitions of Self-Care Need in the Theoretical Phase

Domains of Self-Care Needs	Definition	Sources
Need for changing in behaviors and activities	According to Orem, individuals are able to take care of themselves and this ability is completed by using the knowledge, attitude, skill, and presented in their behavior. When a balance is created between the ability to self-care and self-care needs, the person is healthy. However, when this balance is disturbed, the self-care need create.	Orem, (2001);[35] George (2011)[39]
	Caring as a theory was substructed with analysis of components comprising awareness of a need, knowledge to address the need, assessment of the relationship between the need and intended action, and evaluation of a positive change as an outcome of the action.	Silva (2009)[42]
	Self-care need refers to need for improving practical ability, independency, preventing the behavioral disorders, disability and pain.	Riegel et al, (2012);[36] Hoy et al, (2006);[37] Levin and Idler (1983);[38] Orem, (2001)[35]
	Self-care has been defined as an individuals' ability to reduce or manage the symptoms, cure the physical and mental problems, changing in life style and ultimately having an ideal life. The need or request for self-care is raised when the individual is not able to perform self-care activities.	Hoy et al, (2006);[37] Riegel et al, (2012);[36] Ataee et al, (2014)[43]
	Self-care need is promoting self-help among patients with cancer, enhance positive health behaviors, coping strategies and motivate patients to action.	Hammer (2019)[44]
Supportive care needs	Self-care needs were defined as a set of healthcare services that were raised for patients and their families during the process of diagnosis, treatment, follow-up and the period of improvement.	Sanson- Fisher, (2009);[45] Boyes et al, (2015);[46] Burg et al, (2015)[47]
	This term focus on physician's and healthcare providers' help to continue the care such as giving the require information on follow-up cares and secondary cares, recognition skills, care for disease symptoms, achieving normal condition and health promoting activities.	Campbell et al, (2009);[4] Harrison et al, (2009);[6] Willems et al, (2016);[48] Sarkar et al, (2015);[49] Vanderpool et al, (2017),[50] Molassiotis et al, (2017);[34] Geller et al, (2014)[51]
	Self-care needs focus on rehabilitation, future cares for the personal health, interpersonal and social adaptation, financial and legal support, physical and sexual problems.	Scarton et al, (2018);[52] Fletcher et al, (2017);[53] Riegel et al, (2012);[36] Davy et al, (2015);[54] Riegel et al, (2019);[55] Olsson et al, (2018);[40] Olsson et al, (2018)[41]
	Receiving contributions from relatives, neighbors, colleagues and friends in a process of "shared care".	Riegel et al, (2012);[36] Nekhlyudov et al, (2019);[56] Riegel & Dickson, (2008);[57] Hall et al (2013)[58]

for help to reduce the stress.[65,66] Some themes acquired from qualitative study and systematic reviews are presented in Table 2.

Findings of the Fieldwork Stage

The 19 eligible participants included 12 off-therapy childhood cancer survivors, two parents, two nurses, one physician, one teacher, and one staff from a cancer charity institution. In this research, 13 subjects with off-therapy childhood cancer were enrolled in the study. However, the parents of one child did not allow to interview with their child due to the child's unawareness of the illness and were excluded from the study; therefore, the response rate to the interview was 0.94. The mean current age of children was 13.8 (SD = 2.57) years, 58.69% of them were female, the mean age at cancer diagnosis was 7.89 (SD = 3.78) years, the mean length of treatment was 3.25 (SD = 1.29) and the mean length of off therapy was 1.38 (SD = 0.84) years. Data

Table 2 Extracted Themes from Qualitative and Systematic Review Studies in the Theoretical Phase

Authors	Sample	Method	Purpose	Themes
Campbell and others, (2010)[67]	Cancer survivors	Qualitative study (mixed method)	Psychometric properties of cancer survivors' unmet needs survey	Emotional health needs, accesses to continues care, relationships, financial concerns, informational needs
Patterson and others, (2010)[68]	Young adults sibling with cancer	Qualitative study (content analysis)	Developing an instrument to assess the unmet needs of young people who have a sibling with cancer	Informational needs, peer supporting (friends), peer supporting (similar experience), family support/relationship, expressing/coping with feelings, accessing to supportive services, sleep/entertainment, knowledge/self- attention, instrumental support, involving with cancer experiences.
Cox and others, (2013)[69]	Cancer survivors	Qualitative study (mixed method)	Developing a comprehensive health-related needs assessment for adult survivors of childhood cancer	Psycho-emotional needs, health system concerns, survival information, general health, survival care and support, coping, financial concerns, relationships
Rocha and others, (2014)[70]	elderly cancer patients undergoing outpatient treatment	Qualitative study (content analysis)	Exploring self- care independency in elderly cancer patients undergoing outpatient treatment	Clarifying nutritional concerns, information about physical problems, coping with changes due to living with cancer, family support
Hoekstra, and others, (2014)[71]	Cancer survivors	Systematic review	Assessing health care needs of cancer survivors in general practice	Psychological needs (support, talking about psychological effects of cancer, talking about relationship problems), medical outcomes (nonrelated medical problems, long term effects of cancer), informational needs (general information and response to questions, management of long term effects), support of peer groups, contact with physician, other needs (financial, caring for care provider and family)
Wang and others, (2016)[72]	Cancer survivors	Qualitative study (content analysis)	Exploring unmet psychosocial rehabilitation needs of cancer survivors	Need for better information, psychosocial support, family support of survivors, improving health and medical services, help for financial problems
Berg, and others, (2016)[73]	Cancer survivors	Qualitative study (content analysis)	Exploring young adult cancer survivors' experience with cancer treatment and follow-up care	Information about diagnosis or treatment, receiving survivors healthcare program, physical, social, psychological and school or academic effects, fallow up care problems (limitation in insurance coverage and time, transportation problems, life changing)
Mayer, and others, (2017)[74]	Cancer survivors	Systematic review	Assessing needs and perspectives on survivorship health care	Communicational barriers, coordination between survivors and care providers, need for health care or oncologist support, coping with long term effects of cancer treatment, coping with uncertainly life, fear of recurrence, coping with changes in relationship with others, conservation of self-concept and roles.

analyzing about off-therapy childhood cancer self-care needs indicated two themes of 1) protective self-care needs and 2) supportive self-care needs (Table 3).

Protective Self-Care Needs

Based on the participants' point of view, protective self-care was their main need after treatment. In other words, participants try to hinder the recurrence of cancer by protecting themselves against the risk factors. The two important subcategories were the "need for protection against physical distress" and the "need for protection against psychosocial distress".

One of the off-therapy childhood cancer survivors said about the importance of physical protection:

Table 3 Finding of Data Analysis in Fieldwork Phase

Characteristics	Subthemes	Themes
Protective needs against nutritional risk factors	Protection against physical distress	Protective self-care needs
Protective needs against infection		
Protective needs against physical damage		
Control over cancer recurrence		
Searching information about the disease		
Pain control		
Releasing negative feelings	Protection against psychosocial distress	
Returning to a normal life		
Avoidance the effect of the disease on the family		
Mental support from the family	Empathetic care	Supportive self-care needs
Healthcare companionship		
Communication with friends and community		
Family support for follow-up cares	Cooperation in physical care	
Family help in doing daily routines		
Educating physical care during survival period	Providing information about survival period	
Awareness about long-term effects of cancer		
Providing facilities for the follow-up cares	Instrumental support	
Helps from governmental and non-governmental organizations		
Providing specific educational facilities in schools		

> I must be careful not to catch a cold, but even though I adhere my health, I always get sick more than my classmates; therefore, I must be wear mask in crowded places and eat the foods that are rich and good for me. (Participant 7)

> Also one of the children reported: Most of my teeth are broken, oral health and hygiene is important for me, so my mother reminds me to use mouthwash and fluoride twice or three times a week. I also use soft tooth brush every morning, noon and night. (Participant 4)

Another child said,

> Our family is worried about the possibility of returning the disease, every four-month I refer to the hospital to be checked and they do some diagnostic experiments such as CBC, or ESR. I get lung CT or MRI annually. (Participant 3)

Regarding the protection against psychosocial distress, one of the off-therapy childhood cancer survivors said,

> I'm always upset when my family or other people talking about my disease. I try to uplift my spirits. For example, I may take a trip with my friends to a place where the weather is nice and think about good events in my life. (Participant 7)

Some young adults' children tried to prevent family distress in addition to protecting themselves against psychological distress. For example, one of the young adult said,

> my mother and brother are always anxious about my coughs. They count them and ask me why I coughed more that day. It bothers me when I see my parents' sadness, so I try to hide my physical symptoms not to make them sad. (Participant 5)

Supportive Self-Care Needs

According to the participants' point of view, supportive self-care need is another need. Off-therapy childhood cancer tries to implement self-care activities and when they do

not have the ability and facilities to do that, the necessity of supportive self-care is created.

This category includes four subcategories: "the need for empathetic care", "cooperation in providing physical care", "providing information about the survival period", and "the need for instrumental support".

Regarding the necessity of empathetic care, one of the off-therapy childhood cancer survivors said:

> My family supports me, but they mostly consider my diet. For example, they do not know much about my annoyance of the disease when I am with my friends because they cannot support me emotionally. (Participant 17)
>
> Another child said about cooperation in physical care: "I take my medicines, but my mom always worries about forgetting them and brings the drugs exactly on time. Or, she remembers the exact date of the next doctor visit and cancels all her schedule on that day". (Participant 7)

The oncologist told about providing the patients with information:

> most of the adolescents survivors and their family are worried about puberty, marriage and having babies in the future, I believe that if they are provided with the correct information about body systems or get consultations, a big amount of worries will be removed. (Participant 15)

Instrumental support was one of the emerged sub-themes that included tangible aids such as services, financial aids, and other facilities and specific goods. This kind of support includes the helps that are created when there is a need for or shortage in financial resources.[75]

One of the off-therapy childhood cancer survivors said about the effect of instrumental support of self-care:

> I have to go to another city for follow-up treatments and it costs a lot and takes much time. If these facilities were available in my city, I wouldn't waste my time and I wasn't at risk on the road. It was also economic. (Participant 5)

Another participant said:

> I couldn't keep up with my classmates because of too many absences from school. I have to study in adults' school now. If there were facilities in my school and teachers helped me, I wouldn't go to adults' school. (Participant 18)

Findings of Final Analytic Stage

Theoretical results showed that it is necessary changing in daily behaviors and activities in cancer survivor. Following that, fieldwork results indicated that self-care needs should be met for cancer survivors to maintain a healthy life. These needs are perceived due to the physical, mental, and social vulnerability of the disease. In other words, the need for change in healthcare behaviors arises to prevent and protect against physical and psychosocial side effects. If the patients are unable to implement protective self-care behaviors, the need for support from others is created.

Although the results of the literature review were in agreement with the results of fieldwork, in some cases, the findings of the fieldwork stage were different. The results of the fieldwork analysis show self-care is a preventive action, and there are different levels of prevention that include increasing people's awareness, improving lifestyle and avoiding risk factors, psychological control, and health screening strategy. The results of fieldwork analysis in the category of "the need for protection against psychosocial distress" showed that off-therapy childhood cancer survivors tried to protect not only themselves but also their families from mental distress. In this study, the protection against family mental distress was noticed mainly in young adults' children since they could feel the mental burden in their family; therefore, they tried to prevent the mental effects of their disease on their families.

Another finding that emerged from the fieldwork analysis was "the need for supportive self-care" that was consistent with the results of the literature review. In this process, off-therapy childhood cancer survivors, their families, healthcare providers, and other organizations interact with each other, cooperate in cares, and support the children and families financially, to achieve the maximum rate of health.

Therefore, by synthesizing the findings of literature review and fieldwork, the following definition might be given. Self-care needs in off-therapy childhood cancer survivors is a two-dimensional concept that is perceived as vulnerability because of the physical, psychosocial, and developmental effects of the disease; consequently, the child needs various strategies and activities to protect themselves against physical, psychological distress, and mental distress of their family. If childhood cancer survivors become unable to meet their self-care needs, the need for support in implementing the care is created. Such a need is

presented as “empathetic care”, “cooperation in physical care”, “providing information during survival period”, and “need for instrumental support”. In the other words, off-therapy childhood cancer survivor has three areas for self-care need: the need for controlling the recurrence of disease, the need for better quality of life along with the complications of the disease and the need for normalizing family and social everyday processes. Hence, in addition to self-care activities that a person conducts, the need for support of professional health care such as physicians, nurses, family, government, and charity support is felt by the individual.

Discussion

Nowadays, the concept of self-care is considered as a patient’s right as well as personal responsibility.[76] Individuals are expected to apply some changes in their healthcare behaviors to prevent the disease or to cure it.[77]

The results of the present study showed that children and adolescents need to use some strategies and activities to protect themselves. Besides, protecting the family against mental distress was addressed. Protection is considered as a behavior to prevent potentially harmful incidents such as illness to reduce the negative outcomes resulted from that disease.[78] In this regard, NANDA explains that “ineffective protection” is defined as reducing the ability of individuals coping with internal and external threats. The term is in the class of “health promotion” and “health control”. Protection creates a line of defense against invading physical diseases and improving one’s adaptability.[79] In nursing, protection refers to the fifth basic psychological needs known in the Roy Adaptation Model. This theory focuses on the individual and his relationship with the environment, and the mutual impact between them.[80] Therefore, the protection component is an important adaptation process because through the life defense process the integrity of the body is maintained.[78]

Similarly, Riegel and Dickson (2008) believe that protective self-care is a constructive decision-making process in which applied behaviors might maintain physiological and mental balance and manage any symptoms of the disease.[57] Self-care is the protection of the family, society, and individual against a disease.[81]

In this study, participants considered the need for supportive self-care as a factor to improve their health during the period of survival. Supporting the patient refers to a set of helping activities that underlie the patient’s condition and position as a human being and the response to physical, mental, and social needs through providing information, honoring, respecting, supporting physically, mentally, and emotionally, also protecting, providing, and managing the follow-up cares.[82] According to the World Health Organization (2009), self-care activities are established based on the knowledge and skill of professionals and non-professionals. They are also implemented personally or with participatory or supportive cooperation with the professionals.[16]

As healthcare professionals, the authors intend to empower cancer survivors for self-care or co-care (eg, by enriching the anamnesis and seeking care for sexual dysfunction or fear of recurrence). Therefore, in this study, one learns anything concerning cancer survivors’ empowerment. For example, the internet-based programs developed by psychologists in Aarhus are a step towards empowerment.[83] The age-appropriate and flexible psychological care as well as physical interventions, for example, yoga or dance would be more helpful for this group. [85]

Strengths and Limitations

One of the limitations of the present study is the problem of access to off-therapy childhood cancer survivors because cancer survivors usually go to different health centers to follow-up the disease. Some off-therapy childhood cancer survivors were unaware of their illness; therefore, they could not share their experiences in interviews, so the researchers selected participants who were aware of their illness. The number off qualitative interviews, especially for health professionals, was imitated and it could be interesting to involve other health centers to obtain more information. The strengths of this study were sampling with maximum diversity, which contributes to the richness of data.

Conclusion

Literature review and analysis of the fieldwork stage showed that self-care needs included “need for protective care” and “need for supportive care”. Consequently, analyzing this concept might help the healthcare providers to be aware of off-therapy childhood cancer survivors’ needs and enable them to support the children and their families in implementing the self-care programs by getting knowledge about the nature of these needs. Nursing educators could emphasize the importance of self-care in promoting patients’ health and utilize the definitions in teaching the characteristics of the concept. In the field of management, healthcare officials might take effective steps to institutionalize self-care and

meet the needs. Also, the results of this study could provide a foundation for further studies and researchers might utilize the results to lead their studies on other diseases.

Acknowledgments

The authors appreciate the children, their parents, oncology physicians and nurses of the children hospitals and charity institutes in the city of Tabriz, for their support and consistent cooperation, without which this study could not have been accomplished.

Author Contributions

M.A., L.V., and A.Gh. conceived the study and study design. M.A. and H.M. were responsible for data collection and management. M.A., V.Z., and H.M. contributed to data analysis. L.V. was responsible for writing the original drafts and preparation. V.Z. and A.Gh. helped in the review and editing of the manuscript. All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; took part in drafting the article or revising it critically for important intellectual content; gave final approval of the version to be published; and agree to be accountable for all aspects of the work.

Disclosure

The authors declare no conflict of interest.

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