



Do adolescent cancer survivors need health care and psychosocial services?: An Indonesian experience

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KEYWORDS

Childhood cancer;
Clinical service needs;
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Abstract

Objective: Advances in childhood cancer treatment have contributed to an increased survival rate among childhood cancer patients. The increasing number of survivors means that more help is needed to support them in dealing with the physical and psychosocial problems following their cancer therapy. This study explored the needs of adolescent cancer survivors in terms of health care and psychosocial services.

Method: This qualitative research used a phenomenological approach. Eight adolescent cancer survivors were interviewed using a semi-structured format. The data were analyzed using a thematic analysis.

Results: Seven themes emerged from the study results: (i) follow-up care; (ii) education for patients and their families; (iii) compassionate health care services; (iv) psychological counseling; (v) support from families and friends; (vi) support from school; and (vii) support from social community activities.

Conclusions: These findings showed that adolescent cancer survivors in Indonesia need long term follow-up care for their physical and psychosocial needs. Nurses should play an active role in addressing the needs of adolescent cancer survivors as described in this study.

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Introduction

The incidence of cancer in children increases every year. It was estimated that 175 300 new childhood cancer cases in the world were diagnosed in 2012¹. However, the rising incidence of childhood cancer is accompanied by an upward trend in the survival rate as cancer treatments improve². In Asian countries, for instance in China, the five-year survival rate after a diagnosis of childhood cancer has reached 71.9%². Existing data shows that the life expectancy of children living with or surviving childhood cancer is relatively high and has a positive trend^{2,3}. In Indonesia also, despite

limited data on the survival rate of childhood cancer patients, the advancements in cancer therapy and care would lead one to expect an increasing number of survivors.

Being a cancer survivor does not necessarily mean that a child is entirely free from cancer-related issues. The literature suggests that physical and psychosocial problems resulting from the cancer pathology and its treatments, together with the prolonged nature of these effects, require comprehensive management^{3,5,6}. Some of the physical problems that may develop in childhood cancer survivors are infertility; early menopause; osteoporosis; problems of the heart, kidney, and endocrine system; and also altered de-

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velopment^{7,8}. With regards to the psychosocial aspect, studies find a pattern of frequent psychosocial issues among childhood cancer survivors, which include problems in socializing, behavioral problems, anxiety, depression, somatic problems, fatigue, and sleep disorders^{8,9}.

In Indonesia, an integrated and continuous health care program for childhood cancer survivors is still to be established. The current health care service in Indonesia focuses heavily on cancer therapies and symptom management for pediatric oncology patients. In the United States, with the declining mortality rate from childhood cancer, in 2005, the number of childhood cancer survivors was estimated at 328 653¹¹. In Jakarta alone, 650 children are diagnosed with cancer every year¹². If 40% of those patients survive their cancer, an additional 260 childhood cancer survivors must be added to the number every year. This growing population of childhood cancer survivors need an on-going health care service to address the multidimensional, long-term effects of cancer and its therapies. Therefore, the essential entry point is to identify and explore the specific needs of childhood cancer survivors in Indonesia. This study focused on a description of these physical and psychosocial health care needs as expressed by adolescent cancer survivors.

Method

This study used a qualitative method with a descriptive phenomenological approach. Eight adolescent cancer survivors, aged 10-18 years, participated in this study through the snowballing sampling method. The snowballing process was initiated with help of a keyperson at the Indonesian Pediatric Oncology Foundation. Data were obtained from semi-structured in-depth interviews, which were carried out once with each participant for 30-60 minutes. Data were analyzed through thematic analysis: the transcribed interviews were read and reread to identify key words and to categorize them into themes and subthemes. Ethical clearance was obtained from the ethical committee of the Faculty of Nursing, Universitas Indonesia. We applied the principles of autonomy, beneficence, anonymity, and justice throughout our study. The trustworthiness of this study achieved through member-checking, peer-review, audit trail and thick description.

Results

Seven themes emerged from this study that described the needs of the adolescent cancer survivors (the participants' characteristics can be found in Table 1) for health care and psychosocial care services. These themes were: (i) follow-up care; (ii) education for patients and their families; (iii) friendly health care services; (iv) psychological counseling; (v) support from families and friends; (vi) support from school; and (vii) support from social community activities.

Follow-up care

The issues underpinning this particular need include the late effects of cancer treatment in terms of the physical

Table 1 The characteristics of the participants

Pseudonym	Age (years)	Diagnosis	Age when diagnosed
Faras	17	All	3 years old
Laksmi	18	All	3 years old
Arsa	12	Wilms tumor	8 months old
Tara	13	Abdominal teratoma	3 years old
Nirwa	16	All	3 years old
Adun	17	Juvenile hyaline fibromatosis	5 years old
Ayata	13	All	5 years old
Manda	10	All	2 years old

symptoms and other related symptoms. Some problems might arise due to physical activities, therapeutic regimens, and the failure to adhere to a recommended eating pattern. The participants mentioned that they attempted to rest, to change their routine, or to pay a visit to the health care facility to deal with those problems as described in the following statements:

"I once cried too hard so I was sent into a hospital because I felt suffocated..." (Manda).

"I still hardly hear. It hit my sight and hearing neural system so I cannot see and hear..." (Adun).

Education for patients and their families

Childhood cancer survivors have gone through tough life experiences during their therapies and rehabilitation. Such experiences leave them curious to know more about their illness and the therapeutic process. Furthermore, they realize that inadequate education might lead to their being less than compliant with their cancer care:

"Firstly, I wonder why I got this illness... then of course I wonder why such disease develops..." (Faras).

"I just resisted it, I kept breaking the guidance. So I did what they forbade, such as playing football, eating instant noodles..." (Nirwa).

Friendly health care services

Adolescent cancer survivors have long-standing interactions with the health care services. Growing up in such circumstance places the adolescent in profound need of a friendly, compassionate health care service, housed in proper facilities. The childhood cancer survivors also expect the health care facilities to be convenient. Some of our participants expressed these needs as follows:

"I want toys. I want entertainment, so it will not be boring" (Tara).

"If only they could provide some magazines, I love reading..." (Manda).

Psychological counseling

This necessity arises from the volatile emotional condition that is common in adolescent cancer survivors. The following statements show the survivors' need for supportive psychological care:

"Actually I do not really remember it, as I get hurt when I remember my past. I feel sad, sometimes hurtful..." (Faras).

Such fear might lead maladaptive coping response:

"Sometimes I just get mad at myself. Sometimes when I get angry, I would start hitting myself, hurting myself. I feel terrible, yet I do not want to hurt other people" (Nirwa).

Support from the families and friends

Friends and families are 'significant others' to the adolescent cancer survivor. The family is an inseparable part of the pediatric oncology patient's life, while peer support is critical during the adolescent period. Our participants pointed this out in some of the following statements:

"My friends have been understanding and supportive. They really take care of me" (Laksmi).

However, together with positive support, the adolescent cancer survivor can experience unpleasant treatment from their peer group:

"One time when I was in fourth grade I got bullied, then I was punched in the face... When I was in junior high school, I got some mockeries..." (Adun).

Support from school

School is a second home for children, including those surviving childhood cancer, at which they spend much of their time. Furthermore, cancer survivors need to readapt to the school environment after they have undergone the exhaustive process of cancer therapies. Therefore, support from the school is particularly necessary for this group of adolescents:

"When I was in elementary school, I was so close to my teacher, there was once a teacher who often asked me if I was allowed to eat this and that..." (Faras).

"But sometimes it is difficult to get the permission from school. It is especially true in this high school... I need to get a school leave to have mouth reconstruction at the hospital, sometimes it must be done twice a week. They do not believe me when I ask for permission, they doubt that I am ill" (Adun).

Social community activity support

Social services in Indonesia are commonly provided by the community, by a foundation for cancer patients, or even by other survivors. Nearly all the participants in this study agreed that they needed social services. They would benefit

from such a service by gaining a circle of support, not feeling alone, and having recreational activities, or new knowledge.

"Yes it is important. To keep up our spirit. And when, for example, we are in the recovery phase, we can get more spirit from knowing that we are not alone but there are many that suffer from the disease" (Ayata).

"I would say that I am lucky to have joined the Indonesian Pediatric Oncology Foundation. I often get a bag and diary, and the other day when I returned from Singapore I got a bag, drawing book, and many more things; I got a pencil case too. It is exciting to get such things so I do not have to buy them" (Arsa).

Discussion

This study elucidated seven needs of adolescent cancer survivors in relation to health care and psychosocial services. Those needs are: follow-up care, patient and family education, friendly health care services, psychological counseling, family and peer support, support from school, and social community activity support. Overall, these findings are consistent with the requirements listed in the guidelines for long-term health care services for childhood cancer survivors¹³.

Childhood cancer survivors who experience physical deformity or have a history of organ removal tend to have multifaceted health problems. In the current study, for instance, a participant with a history of Wilms Tumor with renalectomy had more complex problems than most of the other cancer survivors. However, an adolescent survivor of juvenile hyaline fibromatosis, who had had facial cartilage removal and was still undergoing reconstructive surgery, had been suffering from pain in the mouth since the surgery and had lost both his hearing and sight due to neurological injuries. These and similar problems were also found in a previous study among 11 481 childhood cancer survivors with various types of cancer. That study mentioned that 10% of childhood cancer survivors suffer from disturbed sensory perceptions including loss of hearing and blindness¹⁴.

The magnitude of the physical problems faced by childhood cancer survivors provides the background to their need for continuous physical support by the health care services. A prior study called the Childhood Cancer Survivor Study highlighted the risk of chronic health problems, including life-threatening problems, among childhood cancer survivors as being between 3.3 and 8.2 times higher than the risk for their siblings¹⁵. Another study reported on the need for cancer survivors to go through a structured follow-up program since they are susceptible to late effects from their cancer therapy, to lowered health status, and to premature death¹⁶.

Education is essential for adolescent cancer survivors. This study found that these cancer survivors were aware of their need for information regarding their illness, their past and current therapies, and all the related processes happening in their bodies. All this information should be provided and discussed with the patients, the survivors, the families, and the health care team¹⁷. The educational material should be presented in a handy form for the cancer survivor and fam-

ily to carry home. The material should cover all necessary information, including the therapy regimen, the importance of routine follow-up care, a healthy lifestyle, the risk of long-term effects, and their home management¹⁷. In addition, the health care team could adopt other methods of education for childhood cancer survivors, such as psycho-educational interventions, which have been shown to lower levels of stress in cancer patients¹⁸.

Failure to comply with health care management emerged as a subtheme in this study. This adds to the underlying need for health education. Sufficient education for both patient and family raises their self-awareness about the need to maintain health¹⁹. Some survivors in this study confessed they did not follow the recommended eating pattern or physical activity and skipped the follow-up schedule, sometimes for reasons due to past unpleasant experiences with health care facilities, without realizing the risks to which they were subjecting themselves. Similar reasons were reported in a previous study in addition to feelings of weariness in relation to the health care service²⁰.

The participants in the present study reported that they found the health care facilities uncomfortable. They also described the health care providers as being stiff, fussy, and bad-tempered. They wanted a friendly hospital environment which also provided entertainment or media to distract them from their stressful experience during the treatment or care. Moreover, they wanted more communicative and friendly health care providers who would have more positive interactions with them. A study on the experiences of Latino adolescent and young-adult cancer survivors in the United States points out that survivors view the support received from the health care providers, including the nurses, as a substantial part of their treatment, since they see the hospital as their second home and feel at ease talking with anyone there⁵. They experience it as such a pleasant environment that they go to the hospital not so much for their cancer therapy as for fun. This shows that the support and encouragement of the health care team and a comfortable hospital environment may become a source of strength for adolescent cancer survivors.

Childhood cancer survivors have been through traumatic experiences during their battle with cancer and its therapies, together with their side effects, some of which remain long after the treatments cease. In consequence, they have to limit their daily activities and maintain a healthy lifestyle. They frequently feel afraid of the cancer recurring, and suffer from fatigue, physical disabilities, and other physical symptoms. Therefore, they are prone to psychological trauma. One of the findings of this study was the need for psychological counseling. This might arise from a maladaptive response, or the risk of a maladaptive response, in an adolescent cancer survivor, such as negative coping mechanisms, low self-esteem, and a sense of powerlessness. Similar results were found in a study conducted in Hong Kong, where the risk of depression and signs and symptoms of depression were identified in more than half the participants, who were childhood cancer survivors aged 9-16. The childhood cancer survivors in that study were also found to have lower self-esteem than their peers. Some participants in the study, however, showed adaptive responses and did not require psychological counseling. Different conditions, such as cancer type, personality, and peer

and family support, might all contribute to an adaptive response. A previous study that compared the psychological condition of leukemia and non-hodgkins lymphoma survivors with that of their siblings, found that the cancer survivors were at risk for depression and somatic distress as much as 1.6 to 1.7 times more often than their siblings, even though their overall psychological condition was considered to be fine²¹.

All participants in this study agreed with the idea that support from significant others is crucial during the times of survivorship. All participants credited their mothers as having played the most vital role in helping them through their illness and survivorship, while acknowledging the role other family members. At the same time, as with other teenagers, the peer group strongly influences the self identity and social life of adolescent cancer survivors. They need to be accepted in their peer group if they are to build sufficient self confidence. A study in United States by American Society of Clinical Oncology mentioned that brain tumor and leukemia survivors commonly have problems related to school, socialization, and having close friends²². Other research has highlighted that adolescent cancer survivors often feel lonely, anxious about socializing, and have an altered body image²². The current study, interestingly, found that almost all participants had no issues with socialization and gained positive supports from their peers. There was one participant, however, who reported experiencing physical and verbal bullying at school, despite being reasonably good at building close relationships with the other students. All participants in this study mentioned that they had close friends.

Differences in this area might be influenced by the characteristics of Eastern and Western cultures. A qualitative study in a Western context, which focused on the transition of cancer survivors, found that many adolescent cancer survivors restricted their peer interactions due to their physical appearance²⁴. On the other hand, in Indonesia as one of the Eastern country, the values of tolerance and communality are strongly held by the people from a very young age. In the Western culture, people tend to mind their own business, to be individualistic, and independent. This type of culture may contribute to the different issues experienced between east and west and requires further study.

School is the place where children spend the second largest amount of time. It is also a place where childhood cancer survivors can reestablish their previous routines, in line with the other children, after completing their cancer therapy. A theme that emerged in this study was the need for support from the school for childhood cancer survivors, for instance, by giving them permission to attend follow-up care or treatment during the school day and by teachers providing support. Two of the participants expressed concern about problems they were experiencing with a teacher or the school in obtaining leave to attend their routine follow-up treatment at the hospital. A consistent finding, also shown in a previous study, was that adolescent cancer survivors need support from their schools and actually believe that with support from their teachers, family, and peers they will be able to return to normal school life²⁴.

Another finding from the current study was pertinent to community support. All participants in this study stated that they benefited from social services. They were able to share their experiences with the other childhood cancer survivors

and learn new things and self-actualize through the activities of the social services. They also got great encouragement and optimism from this social circle. Shared and supportive activities are indeed beneficial for childhood cancer survivors²⁵. Meeting with other cancer survivors may help an adolescent to become more comfortable with themselves, to have greater self-esteem, and to get the feeling that they are not alone as they suffer from cancer.

This study, however, has some limitations. One of them is a lack of heterogeneity among the participants in terms of their cancer types. Different cancer types might lead to different experiences, thus enriching the qualitative data, but we found few childhood cancer survivors of those other cancer types. In addition, two of the interviews in our study were abruptly interrupted by the mothers and that might have distracted the focus of the participants.

Nurses should play an active role in addressing the needs of the adolescent cancer survivor as described in this study. Further interventions and strategies should be developed, for instance, by applying the guidelines of follow-up care, or by providing nursing care that takes into account the risk of late effects from cancer treatments. Nurses should also emphasise their role as patient educators and provide the patient and family with education according to their needs and priorities. In addition, there is an expectation that nurses should become both more compassionate and more jolly when interacting with adolescent cancer survivors.

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