



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

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KEYWORDS

Childhood cancer;
Clinical service needs;
Survivors;
Psychosocial needs

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).

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