



Pediatric Palliative Care in Armenia: A Qualitative Analysis of the Needs of Adolescents with Cancer and their Parents

Armine Abrahamyan¹, MPH; Tsovinar Harutyunyan¹, MPH, PhD; Sarah Kagan², PhD, RN

¹School of Public Health, American University of Armenia, Yerevan, Armenia

²School of Nursing, University of Pennsylvania, Philadelphia, USA

BACKGROUND

According to the needs assessment conducted by Open Society Foundations in Armenia approximately 18,000 adult patients per year are in need of palliative care. Although efforts have been made to assess the palliative care needs of adults, no focused investigation of the pediatric palliative care has been conducted in Armenia to date.

In Armenia, the incidence of all types of cancer among children 0-14 years old was 9 per 100,000 population, while among adolescents 15-17 years old it was 11.8 per 100,000 population in 2013. The aim of the study was to assess the pediatric palliative needs of adolescents with cancer and their parents.

METHODS

A qualitative approach was adopted to assess the pediatric palliative needs of adolescents with cancer and their parents.

Adolescents receiving care at one of the three oncology/hematology hospitals were purposefully sampled. In depth interviews were conducted with adolescents and their parents at hospitals and at participant's residences. Seventeen in-depth interviews were conducted among adolescents (10-19 years old) diagnosed with all types and stages of cancer and their parents, using a semi-structured interview guides.

The interview guides were developed using the domains of palliative care described by the WHO and the National Consensus Project for Quality Palliative Care. Directed content analysis was used to analyze the data.

RESULTS

The major challenges that were experienced by the participants throughout the treatment continuum included financial burden due to out-of pocket payment for the chemotherapy drugs, the unavailability of certain chemo drugs, inadequate hospital conditions, absence of individual psychological counseling for both adolescents and their parents, as well as not having opportunities for adolescents to continue their education while receiving the treatment in the hospitals.

“There are drugs that are not available in hospital and we have to buy them. Basically we buy drugs for the treatment. The drugs are very expensive, for the first courses of treatment we bought “Natulan”, which is very expensive, approximately 625.00 USD”.

“Sometimes there is no medication in the hospital and we should buy it. Moreover, sometimes we cannot find the needed medication in Yerevan and we should order it from another country. Because of these difficulties my child may not receive the needed medication on time”.



Art craft during psychological counseling with pediatric oncology patients, Yerevan, Armenia

“I do not like my patient room, as the walls are wet. In the mornings when I wake up there is water on the window sill, the patient room is narrow and small. It [patient room] is warm. We share the room with another child and his mother. My mom and I sleep on one bed; we do not have a toilet and a bathroom”.

“I have never had such [individual] conversation with my psychologist. I would like to talk to her, as I cannot talk to my mom..... My mom cries all the time”.

“Learning is a priority for me. I love learning. I would like to continue my studies in the hospital. One teacher may come for several hours and teach us. Or if there is a Wi-Fi in the hospital I may bring my notebook and by Skype hear and see what is going on in the classroom.”

All adolescents and their parents who participated in the study described their relationship with physicians and nurses as very “supportive”, “attentive”, “open”, “close”, and “trustworthy”.

“I have a very good and friendly relationship with doctors and nurses. They [the doctors and nurses] do not treat me like a child; they [the doctors and nurses] treat me like an adult. They [the doctors and nurses] visit me frequently to do injections, to give drugs and to get informed about my health”.

CONCLUSIONS

Although the care for pediatric oncology patients in Armenia is free, most of the parents paid for the drugs for treatment and imported some of the drugs from abroad whenever the drugs were unavailable at the local pharmaceutical market. Our study results revealed that neither parents nor adolescents received adequate psychosocial counseling in hematology/ oncology hospitals. An important finding pertained the experience of adolescents regarding the student absenteeism from school. Adolescents who studied at school or college at the time of treatment regretted the disruption of school.

We hope that this assessment will help to direct greater attention to the needs of adolescents diagnosed with cancer and their parents in Armenia.

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