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 care 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.

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.

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.

“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.”

“I have a very good and friendly relationship with doctors and nurses. They treat me like a child; they treat me like an adult. They visit me frequently to do injections, to give drugs and to get informed about my health.”

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”.

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. Out 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.

AKNOWLEDGMENTS

Special appreciation is extended to adolescents facing cancer and their parents for sharing their experience.

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