

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

Master of Public Health Integrating Experience Project

Professional Publication Framework

by

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## TABLE OF CONTENTS

ACKNOWLEDGMENTS.....	iii
LIST OF ABBRIVATIONS .....	iv
ABSTRACT.....	v
INTRODUCTION .....	1
<i>Pediatric palliative care: definition and magnitude .....</i>	<i>1</i>
<i>Fundamental elements of pediatric palliative care.....</i>	<i>3</i>
<i>Situation in Armenia.....</i>	<i>8</i>
METHODOLOGY .....	11
<i>Study design.....</i>	<i>11</i>
<i>Study population.....</i>	<i>11</i>
<i>Data sources.....</i>	<i>11</i>
<i>Participants' recruitment and Data collection .....</i>	<i>12</i>
<i>Study instrument.....</i>	<i>12</i>
<i>Data management .....</i>	<i>13</i>
<i>Data analysis.....</i>	<i>13</i>
<i>Ethical considerations.....</i>	<i>14</i>
<i>Socio-demographic characteristics of participants.....</i>	<i>14</i>
<i>Structure and processes of care (including Hospital conditions) .....</i>	<i>16</i>
Cost of the treatment/drugs .....	16
Drugs' availability .....	17
Financial support received from others .....	18
Conditions of the patient rooms .....	19
Conditions of the department .....	21
Awareness of the treatment received .....	24
Best treatment from parents' perspective .....	24
<i>Physical domain.....</i>	<i>25</i>
Pain assessment and control .....	25
Treatment-related symptoms management.....	27
<i>Psychological domain .....</i>	<i>28</i>
Adolescents' understanding of cancer diagnosis .....	28
Adolescents' acceptance of long-term illness and confinement to the hospital.....	30

Fears and anxiety about the treatment .....	30
Psychological services for adolescents .....	30
Psychological services for parents .....	32
<b><i>Social domain</i></b> .....	<b>33</b>
Communication with health care providers .....	33
Communication with family members .....	35
Communications with friends and school mates.....	37
<b><i>Spiritual domain</i></b> .....	<b>38</b>
Cancer as a life-changing event .....	38
Special connection with God.....	40
<b><i>Study Strengths and Limitations</i></b> .....	<b>46</b>
<b><i>Conclusions</i></b> .....	<b>47</b>
<b><i>Recommendations</i></b> .....	<b>47</b>
REFERENCES .....	49
APPENDICES .....	55
<i>Appendix 1. Interview guide for adolescents with cancer (English version)</i> .....	55
<i>Appendix 2. Interview guide for adolescents with cancer (Armenian version)</i> .....	57
<i>Appendix 3. “0–10 Numeric Pain Rating Scale” (English and Armenian versions)</i> .....	60
<i>Appendix 4. Interview guide for parents of adolescents with cancer (English version)</i> .....	61
<i>Appendix 5. Interview guide for parents of adolescents with cancer (Armenian version)</i> .....	65
<i>Appendix 6. Data collected from child’s medical record (English and Armenian versions)</i> .....	70
<i>Appendix 7. Consent form for parents (English version)</i> .....	71
<i>Appendix 8. Consent form for parents (Armenian version)</i> .....	73
<i>Appendix 9. Consent form for 19 years old Adolescents (English version)</i> .....	75
<i>Appendix 10. Consent form for 19 years old Adolescents (Armenian version)</i> .....	77
<i>Appendix 11. Assent form for Children Ages 10-18 (English version)</i> .....	79
<i>Appendix 12. Assent form for Children Ages 10-18 (Armenian version)</i> .....	80
<i>Appendix 13. IRB approval letter</i> .....	82

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## LIST OF ABBRIVATIONS

APA-American Psychological Association

AUA- American University of Armenia

CNS- Central nervous system

EAPC -European Association of Palliative Care

ICU- Intensive care settings

IDT- Interdisciplinary team

IRB-Institutional Review Board

LMIC -low-income and middle-income countries

MoH- Ministry of Health

NIH-National Institute of Health

OSF- Open Society Foundations

PPC-Pediatric Palliative Care

WHO-World Health Organization

## ABSTRACT

According to WHO, Pediatric Palliative Care (PPC) is an active and total approach, embracing physical, psychological, social and spiritual elements of children care. Palliative care is appropriate for children with a wide range of conditions even when cure remains a distinct possibility.

As soon as a child has been diagnosed with cancer, palliative care becomes an essential part of cancer control. Although cancer in children is rare, it is the leading cause of disease-related death among children and adolescents in the United States, with the annual incidence rate of 186.6 per 1 million children ages 0-19. 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. No focused investigation of the pediatric palliative care has been conducted in Armenia and little is known about the needs of pediatric cancer patients and their parents.

The aim of the current study was to assess the pediatric palliative needs of adolescents with cancer and their parents. The student investigator conducted seventeen in-depth interviews among adolescents (10-19 years old) diagnosed with all types and stages of cancer and their parents, using a semi-structured interview guide. The interviews were conducted in The National Center of Oncology, The Hematology Center, and “Muratsan” University Hospital, as well as at participants’ homes. Directed content analysis was used to analyze the data. The important challenges that were experienced by the participants throughout the treatment included financial burden of the treatment, the unavailability of certain drugs for chemotherapy treatment, inadequate hospital conditions, absence of individual psychological counseling for

both adolescents and parents, as well as not having opportunities for adolescents to continue their education while receiving the treatment in the hospitals.

The findings of this study will help to direct greater attention to the needs of adolescents with cancer in Armenia and their parents.

## INTRODUCTION

### **Pediatric palliative care: definition and magnitude**

The Latin word “palliate” means “conceal or alleviate symptoms without curing”.<sup>1</sup> According to the World Health Organization (WHO) Pediatric Palliative Care (PPC) is an active and total approach, embracing physical, psychological, social and spiritual elements of children care.<sup>2</sup> The National Consensus Project for Quality Palliative Care (USA) expands the scope of palliative care provided by WHO and includes several other domains of care; structure and process of care, cultural aspects of care, care of the patients at the end of the life, and ethical and legal aspects of care.<sup>3</sup> Palliative care focuses on the improvement of quality of life for the child and support for the family, through early identification and impeccable management of distressing symptoms.<sup>2</sup>

Palliative care is appropriate for children with a wide range of conditions even when cure remains a distinct possibility. According to the European Association of Palliative Care (EAPC) life-limiting and life-threatening diseases are eligible for palliative care.<sup>4</sup>

Life-limiting illness is defined as a condition where premature death is usual (for example, Duchene muscular dystrophy).<sup>4</sup> Life-threatening illness is one where there is a high probability of premature death due to severe illness, but there is also a chance of long-term survival to adulthood (for example, children receiving cancer treatment).<sup>4</sup>

Four different categories of childhood diseases have been identified by the Association for Children with Life-threatening or Terminal Conditions and the Royal College of Pediatrics and Child Health:

1. Life-threatening conditions for which curative treatment may be feasible but can fail, where palliative care is provided together with attempts at curative treatment (cancer, irreversible organ failure);

2. Diseases which are life-threatening at an early age, where appropriate treatment may prolong life and provide an adequate quality of life (cystic fibrosis);

3. Progressive conditions without curative treatment options, where treatment is exclusively palliative (some chromosomal diseases, muscular dystrophy, rare metabolic diseases);

4. Non-progressive, irreversible conditions, with complex healthcare needs, that give rise to many complications and premature death (severe cerebral palsy, brain or spinal cord injuries due to trauma or infection).<sup>4</sup>

Annually, approximately 53,000 infants and children die and 500,000 children cope with life-threatening conditions in the United States.<sup>5,6</sup>

Although cancer in children is rare, it is the leading cause of disease-related death among children and adolescents (ages 1 to 19 years) in the United States.<sup>7</sup>

According to the statistics provided by the American Cancer Society in 2014 approximately 15,780 new cases of cancer will be diagnosed and 1,960 deaths from cancer will occur among children and adolescents ages 0-19 years in the United States.<sup>7</sup> Annual incidence rate of cancer in children and adolescents is 186.6 per 1 million children ages 0-19.<sup>7</sup> Several studies indicate that majority of children with complex chronic conditions (including malignancy) (87%) were in an intensive care settings (ICU) at the time of death. Most deaths occurred in the pediatric critical care unit (56%), followed by the neonatal intensive care unit (31%).<sup>8-10</sup> In the UK, children who are receiving potentially curative treatment are more likely

to die in hospital (where they will receive intensive care), meanwhile children who are receiving palliative treatment are more likely to die at home or in a hospice.<sup>11</sup>

According to the data summarized by American Cancer Society, most common types of cancers that occur during childhood and adolescence are acute lymphoblastic leukemia, brain and central nervous system (CNS) tumors, neuroblastoma, lymphoma (Hodgkin lymphoma and Non-Hodgkin lymphoma), nephroblastoma, embryonic tumors, sarcomas of bone and soft tissue, retinoblastoma.<sup>7</sup>

According to World Health Organization (WHO) as soon as a child has been diagnosed with cancer, palliative care becomes an essential part of cancer control.

Although pediatric and adult palliative care (PC) share common features, pediatric patients have very unique needs and they cannot be considered as merely “little adults”.<sup>12</sup> There are numerous peculiarities to consider, including the limited number of pediatric cases of chronic/terminal disease, variable types of disease and their duration, specificity and complexity of services required, the role of family, emotional involvement of family members and healthcare providers, developmental factors that influence the child’s understanding of illness and death, as well as their ability to communicate and participate in decision-making, and the ethical and legal issues.<sup>4,13</sup>

Pediatric patients should receive concurrent palliation and disease-directed therapy, as well as they require age-appropriate medication dosing due to physiological and psychological differences.<sup>12</sup>

### **Fundamental elements of pediatric palliative care**

Physical domain is considered as cornerstone of providing pediatric palliative care for oncology patients and includes pain and symptoms management.<sup>14</sup> Bereaved parents have

reported that fatigue, pain, dyspnea, nausea, and poor appetite were the most common physical symptoms experienced during their child's last days of life.<sup>15-18</sup>

Research suggests that adolescents (10–18 years of age) with cancer have reported fatigue severity scores in the moderate to severe/very severe range over the course of chemotherapy.<sup>19</sup> Despite the fact that fatigue is most frequently reported symptom and has been associated with increased anxiety, sadness, and fear at the end of life, it remains one of underreported and undertreated symptoms in pediatric oncology patients.<sup>14,17</sup>

Pain is one of the most studied, though not the best controlled symptoms in cancer. Pain in cancer could be caused by the disease, treatment and medical procedures.<sup>20</sup> Pain management for a child with a life-threatening condition should be conducted not just at the end of life, but throughout the course of illness, which may run years after the initial diagnosis.<sup>21</sup> According to parental reports, 89% of children who had died of cancer, experienced substantial suffering from at least one symptom, most commonly fatigue, pain, or dyspnea. Less than 30% of parents reported that the treatment of pain was successful, and only 10% reported that nausea and vomiting or constipation was controlled.<sup>17</sup>

Chemotherapy- induced nausea and vomiting is another distressing symptom experienced by children and adolescents.<sup>14,21,22</sup> Nausea and vomiting often depend on chemotherapy agents used.<sup>14</sup>

*Psychological domain* includes the child and family members' fears and concerns related to the disease, coping mechanisms, and their overall perception of life and death.<sup>14,23</sup> Psychological symptoms reported by adolescents facing cancer are depression, sadness, anxiety, nervousness, worry, guilt, loneliness, and fear.<sup>5,14,24</sup> Studies indicate that parents of both newly diagnosed children and children who are in the different stages of the treatment experience

increased emotional distress (anxiety, depression), as well as insomnia or somatic and social dysfunctioning.<sup>23-25</sup> Research shows that in various phases of their child's disease 34 % of mothers were diagnosed with psychiatric disorder.<sup>25</sup>

Social domain includes adolescents' interaction with/or isolation from others. Social support is an important element for children with life-threatening conditions and may emerge via social networks.<sup>14</sup> Social interactions between teens with cancer, giving and receiving inspiration from each other, give an opportunity to act as a normal teenager. On the other hand support from healthy friends is often limited.<sup>14</sup> In several studies parents of pediatric oncology patients reported that support from family members, friends and other parents was the most helpful for them.<sup>17,25</sup> Most parents also report that they receive support from either family or friends for the siblings of children with cancer.<sup>17</sup>

Spirituality in PPC is described in a broader sense than religion, being related to issues such as the meaning and purpose of life, how sick children understand the meaning of life, death, and includes concerns such as unconditional love, forgiveness, hope, safety, security and legacy.<sup>14,26</sup>

Structure and processes of care occur across the health care spectrum. In order to provide high quality palliative care, interdisciplinary team is required, which includes palliative care professionals with the appropriate patient-population-specific education and experience (physicians, nurses, social workers, nutritionists, respiratory therapists, pharmacists, psychologists, chaplain, speech and language pathologist, etc.).<sup>27</sup> The structure and processes of care ensure delivery of palliative care in a safe physical environment that meets the needs of patients and family with respect for their values, preferences, and wishes.<sup>3,27</sup>

Cultural aspects of care require that across the care continuum, palliative care teams meet the needs of the patients and their family members in a culturally sensitive manner.<sup>3</sup> Cultural aspects of care accentuate "culture and linguistic competences" that refer to the palliative care teams to respond respectfully and effectively to "people of all cultures, and national origins; socioeconomic status; sexual orientation; spiritual, religious, and political beliefs and affiliation; physical, psychiatric, and cognitive ability, including health and financial literacy".<sup>3</sup>

Care of the patient at the end of life Sign and symptoms of impending death should be recognized and documented appropriately. End-of-life concerns, fears, hopes, and expectations should be discussed openly and honestly with patients and family members. Ideally, sensitive communication is done around autopsy and organ donation decision making before the time of death as appropriate. Post death care should be delivered in a respectful manner based on patient-family preferences.<sup>3</sup>

Ethical and legal aspects of care emphasize the importance of provision of palliative care in accordance with professional, state, and federal laws, as well as in accordance with regulations and accepted standards of care. In the care of pediatric oncology patients' ethical and legal aspects of care included child's views and references for medical care. When the child's wishes are different from those of parents, professional staff members should be available to assist both the child and the family.<sup>3</sup>

### **Pediatric palliative care needs assessment**

It is widely recognized that pediatric palliative care (PPC) services that offer integrated care for children and adolescents with life-limiting/life threatening illness have improved their survival and quality of life. PPC service provision varies depend in different parts of the world. A systematic review of PPC provision across many countries has been undertaken in 2011.<sup>28</sup>

The results have shown that 65.6% of countries did not have pediatric hospice-palliative care services, 18.8% had recognized capacity building activities, 9.9% countries provided localized services, and 5.7% had integrated pediatric palliative care with mainstream service providers.<sup>28</sup>

There have been several studies that investigated the needs of pediatric patients, their caregivers, and healthcare professionals who are delivering the care. These studies highlighted the importance of conducting a comprehensive audit of existing services available to children with palliative care needs, as well as current and anticipated palliative care needs of children with life-limiting/threatening conditions over the course of their illness.<sup>29-31</sup>

The results of a national pediatric palliative care needs assessment undertaken in Ireland showed that adolescents who are diagnosed with life-limiting and life-threatening conditions are in need for improved facilities when receiving treatment in hospital, they are in need for privacy, interaction and communication with their own peer group, open communication with trusted adults, other than parents, as well as engagement in collaborative decision-making with parents and professionals.<sup>29</sup>

Several studies have shown that parents were generally satisfied with the care provided for their children, though they identify the following obstacles for adequate pediatric palliative care; poor communication with health care professionals, poor physical conditions in some hospital settings (e.g. no privacy or comfort, dirty toilets, dirty laundry and parents sleeping on a fold-up bed or chair), as well as inappropriate ward conditions that are not always suitable for adolescent care (reference). Parents also report that the follow-up psychological and bereavement support for families is not always available through hospital structures.<sup>29-31</sup>

### *Situation in Armenia*

The Republic of Armenia is a lower-middle income country with the population of 2,977,000.<sup>32</sup> According to the statistics provided by the National Institute of Health (NIH) 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.<sup>33</sup>

The establishment of the system of palliative care in Armenia as a separate domain of care on a national level has started in 2009. In 2009 palliative care has been included in the list of medical services in the Governmental Decree N 276-N dated 27.03.2008.

In the same year in close collaboration with the Pain Control and Palliative Care Association (established in 2004) and the Ministry of Health (MoH), Open Society Foundations of Armenia (OSF) conducted palliative care needs assessment for adults.<sup>34</sup> The aim of the assessment was to develop the firm basis for national palliative care implementation. According to the assessment up to 3,000 patients per day and approximately 18,000 patients per year are in need of palliative care in Armenia. In order to provide home-based and inpatient care both for urban and rural areas approximately 600 nurses, 120 physicians, and 300 other clinical support staff would be required.<sup>34</sup> The assessment highlighted several aspects of palliative care that should be addressed by future interventions in this area. Lack of policy guidance from Armenian Government was identified as the main obstacle to national palliative care development and implementation.

Pain control in palliative patients has been mentioned among the most challenging aspects of the current system. The Government Resolution of 2001, approving prescription forms and the Minister of Health Decree on prescribing rules of 2002, allow a prescription for opioids to be valid for 20 days from the day it is written; however, the Law on “Narcotic Drugs

and Psychotropic Substances” of 2002 allows a prescription for opioids to be valid for 10 days from the day it is written. Meanwhile, the only pharmaceutical company that imports opioids into Armenia follows a practice of providing opioids only if the prescription is written on the same day. Prescriptions mostly provide opioids for 2-3 days need. The practice of only filling an opioid prescription for 3 days leads to considerable frustration. Patients who are able to get a prescription from their local outpatient polyclinic have a hard time getting more than a 3-day supply of medication in injectable ampoule form and at limited dosage. Also it is required that patients return used ampoules before more could be obtained. Some patients require large doses of opioids to achieve pain control and they have to take these medications around the clock. There is no effective limit on the dosage that can be taken.

In addition most physicians are not able to prescribe opioids. Although there is no regulation restricting the right of physicians to prescribe opioids, prescriptions are done only by local outpatient polyclinic oncologists. The Government included opioids for cancer patients in the list of medicines to be purchased centrally, thus medications are only available through this system. Patients in rural areas have difficulty in obtaining opioids. In rural areas there are absences of drugstores that have permission to supply narcotics, and patients have to visit Yerevan or regional centers to get a three-day supply of drugs.

The findings of assessment indicated that a number of institutions are interested in providing palliative care education to health care professionals. Despite its obvious importance there is no palliative care residency or fellowship programs leading to specialization for Armenian healthcare professionals. Two main policy documents endorsed by the government served as a legal ground for this initiative. In 2012 the Government of Armenia approved the “Concept of Palliative Care in Armenia” (08.09.2012 protocol number 32) and in 2014

Government registered two subspecialties: pain management and palliative care (04.09.2014 protocol number 952-N).

Based on the needs assessment the document on the National Standards for Palliative Care implementation has been drafted and is expected to be approved by the Government of Republic of Armenia by 2016.

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 order to address this gap, we conducted the assessment of the needs of adolescents with cancer and their parents. The findings of this assessment will add the perspectives of adolescents and their parents to our knowledge about pediatric palliative care in Armenia and will help to improve the services provided to them in Armenia.

The study addressed the following research questions:

1. What are the palliative care experiences of adolescents diagnosed with childhood cancer and their parents/caregivers?
2. What are the palliative care needs of adolescents diagnosed with childhood cancer and their parents/caregivers?

## METHODOLOGY

### *Study design*

To address the research questions a qualitative study with semi-structured in-depth interviews was conducted. The study employed directed content analysis. The student investigator used case-based sampling to recruit adolescents living with cancer and their parents in the study.

### *Study population*

Two groups of participants were involved in the study:

- Adolescents (10-19 years old) diagnosed with all types and stages of cancer.
- Parents and /or legal guardians of adolescents diagnosed with childhood cancer.

The age range of participants was chosen based on WHO definition of adolescents. WHO defines an adolescent as any individual between ages 10 and 19.<sup>35,36</sup>

Adolescents have been registered and receiving treatment at one of the three Hospitals (The National Center of Oncology, The Hematology Center, and “Muratsan” University Hospital) where pediatric cancer care is provided in Armenia. Parents and /or legal guardians of those adolescents with available contact information, willingness to participate, fluency in Armenian or Russian and residents of Armenia have also been interviewed in the scope of this study.

### *Data sources*

Data were collected through semi-structured in-depth interviews. Additional data including diagnosis, age at diagnosis, length of treatment, and required medical treatment we collected from the medical records of pediatric patients.

### *Participants' recruitment and Data collection*

The heads of oncological departments gave permission to conduct the study in the premises of hospital wards. The student investigator approached those physicians who provide treatment to pediatric patients. Afterwards, physicians who treated adolescents diagnosed with childhood cancer provided the contact information of their parents/caregivers. Physicians introduced the purpose of the study to the parents/caregivers and obtained their preliminary agreement to participate in the study. The student investigator contacted them and obtained their permission to participate in the study, and the permission to interview their children. Taking into account the vulnerability of pediatric patients, additional permission was obtained from the treating physician to assure that there were no contraindications to approaching children (e.g. weakened immune system). Afterwards, student investigator approached adolescents and explained the aim of the study, as well as study-related procedures in the presence of their parents.

### *Study instrument*

In-depth interviews were conducted using two semi-structured interview guides (Appendices 1-5) which consisted of open-ended questions. The instrument was developed by the research team based on the literature on fundamental domains of palliative care. The questions were grouped into following domains.

1. Structure and processes of care (including hospital conditions)
2. Physical domain
3. Psychological domain
4. Social domain
5. Spiritual domain

Individual interviews were held with adolescents diagnosed with childhood cancer and their parents at a time and place (hospital, home) convenient for them. The data collection stopped after the saturation was achieved. After the interviews, parents and adolescents were offered one session of free psychological counseling by the student investigator who has a master degree in clinical psychology and 2 years of working experience with children living with cancer.

#### *Data management*

The student investigator transcribed all recordings and notes into Armenian. All participants were assigned ID numbers. No personal identifiers (such as name of the patient, phone number, address) were collected during study. Audio recordings were password protected and were destroyed along with the paper data forms at the end of the study. Only student investigator and advising team had access to the data.

#### *Data analysis*

The student investigator coded and categorized data according to palliative care domains by WHO (physical, psychological, social and spiritual domains), and the domain of structure and processes of care that was identified by the National Consensus Project for Quality Palliative Care. The coding process included two cycles. During the first cycle all meaningful words or/and sentences were highlighted and written in a separate column (Initial Coding).<sup>37</sup> During the second cycle of coding the student investigator grouped similarly coded data into categories. Other themes that emerged during the analysis were carefully analyzed and labeled.<sup>37</sup>

The rigor and trustworthiness of the study had been ensured through: 1) frequent debriefing sessions with advising team in order to widen the vision of the student investigator, 2) appropriate background, qualifications and experience of the investigator, as well as 3) helping

to ensure honesty in informants, by assuring each of the participant that they can refuse to participate in the study at any moment.<sup>38,39</sup>

Individual viewpoints and experiences were triangulated between the adolescents with cancer and their parents. To sustain credibility, the student investigator interviewed adolescents and parents from three different Oncology Hospitals in order to reduce the effect of particular local factors peculiar to one hospital on the study findings. In order to address dependability or reliability, the study included precise description of the research design and data collection process.

#### *Ethical considerations*

Parents and /or legal guardians of adolescents with cancer gave thier written consent before conducting interviews for their own and their children's participation in the interview. Participants were informed about potential stress that the interviews may cause, and specific procedures in place to assure their comfort (e.g. psychological counseling). Student investigator obtained assent from adolescents before proceeding to interviewing. Personal information obtained during the study was used for the purposes of research only. The researcher made audio-recordings only with permission of the participants. The quotes from participants included in this study were de-identified. The Institutional Review Board of the American University of Armenia reviewed and approved the study protocol.

## RESULTS

#### *Socio-demographic characteristics of participants*

Nine mothers and eight adolescents diagnosed with different types of cancer participated in the in-depth interviews. Overall, 17 in-depth interviews were conducted, with three of them

conducted at participants' home and 14 in hospital settings. Psychological counseling followed the interviews with 6 mothers and 3 adolescents, with mean session duration of 1 hour.

The mean age of mothers was 37, ranging from 32 to 40. All women identified themselves as Armenian. The majority of mothers had only 10 years of school education, were unemployed at the time of the study, had two or three children, were from marzes, and were married. Most of the families were spending between 138,500 and 200,000 AMD ((\$288 - \$416.00) per month (Table 1).

Table 1. Socio-demographic and personal characteristics of mothers

<b>Characteristics</b>	<b>N</b>
<b>Residence</b>	
Yerevan	2
Marzes	7
<b>Relationship with adolescents</b>	
Mother	9
<b>Age, Mean (Range)</b>	37 (32-40)
<b>Marital status</b>	
Married	8
Widowed	1
<b>Education</b>	
School	5
Professional technical education	2
University	2
<b>Employment</b>	
Employed	1
Unemployed	8
<b>Number of children</b>	
1-2	5
3 and more	4
<b>Number of families registered in PAROS</b>	6
<b>Monthly expenditures, Mean (Range)</b>	138,500-200,000 AMD (51,000-301,000AMD)

Two female and six male adolescents participated in the study. The mean age of adolescents with cancer was 15, ranging from 12 to 19. Oncology patients were recruited from three Hospitals; the National Center of Oncology (1), the Hematology Center (5) and “Muratsan” University Hospital (2). Four out of eight adolescents had been diagnosed with acute lymphoblastic leukemia, two of them were diagnosed with Hodgkin's lymphoma, and two adolescents had sarcomas. One adolescent who was diagnosed with acute lymphoblastic leukemia had a speech disorder and was not able to participate in the interview. Only the mother of this adolescent was interviewed. Six out of eight adolescents have not undergone a surgery, had been diagnosed with cancer between 2013 and 2015, and were receiving chemotherapy at the time of the study. Only two adolescents have been receiving both chemotherapy and radiation.

### **Structure and processes of care (including Hospital conditions)**

#### Cost of the treatment/drugs

Although parents who participated in the study reported that the treatment of pediatric oncology patients is free of charge in Armenia, almost all of them had to buy chemotherapy drugs for their children. Parents who participated in the study mentioned that the price paid for each course of treatment varied according to the drugs and the treatment scheme, from 200,000 AMD to 1,500,000AMD ((USD 420.00- 3,125) and more.

“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 300,000 AMD (USD 625.00)”.

P., 34

“We receive our treatment free of charge. There are some drugs that the hospital does not provide, we buy them ourselves. Some drugs are very expensive. On the average we spend more than 200,000 (USD 420.00) drams for the treatment per month, including fare and food. Whether we will afford [the treatment] or not, we must cure her [the daughter]”.

	P., 37
“For one course of treatment we pay 1,000,000 -1,500,000 AMD (USD 2,080- 3,125). The amount depends on the drug “Neupogen”. If we need to inject 10 ampoules of “Neupogen”, this is already 600,000 AMD (USD 1,250), plus other drugs”.	
	P., 40
“Treatment is free of charge. For this first course of treatment I have already bought drugs for 300,000 AMD (USD 625.00). I expect that the drugs will be much more expensive for the next courses, plus food (natural juice, boiled meat, fresh fruits, etc.)”.	
	P., 39

### Drugs' availability

Several parents mentioned that the drugs used for chemotherapy for their children were mostly available in Armenia, while some of them reported that they had to find drugs abroad, as prescribed drugs were not registered in Armenia.

“Sometimes we do not take the drugs that doctors prescribe, as they are from China, and we buy the same drugs made in Europe. Once we paid \$100 only for anti-nausea drug”.	
	P., 38
“My son needs Daunorubicin drug that is not available in Armenia. My son needs 9 ampoules but I have only 5. The hospital cannot provide my son with this drug, as it is not registered in Armenia, but if the treatment is based on this drug, I must find it..... In case I cannot find the drug, I know a patient that can sell it to me. One ampoule costs 10,000 AMD (USD 20.00), I need 4 ampoules.	
	P., 39

Several mothers complained that because some drugs are not available, their child may not be able to receive the needed medication on time.

“Lack of medication is the main problem. 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”.	
	P., 37
“The main problems are lack of financial resources and lack of drugs. Sometimes it is very difficult to get the drugs, sometimes I do not have enough money”.	
	P., 39

Financial support received from others

Vast majority of parents who participated in the study noted that they received financial support from “Grant Life” Armenian Charitable Foundation. According to parents they bought the drugs that were not available in the hospital and gave the cheques to the Foundation for compensation. One of the parents mentioned that she received drugs for her son from another woman, whose grandson died because of cancer.

“It would be unaffordable for us to treat our child, but thanks God, “Grant Life” is next to us, and they help us a lot. When we buy the drugs, we give them the cheques, and they compensate it. Sometimes they delay the compensation, but eventually they pay. They compensated a large sum of money, first time it was 380,000 AMD (USD 790.00), and the next time it was 600,000 AMD (USD 1,250)”.

P., 34

“We receive support from the Armenian Charitable Foundation “Grant Life”. We buy the drugs and give them the cheques, and they reimburse the sum”.

P., 37

“We have debts; we borrow money from banks, from our relatives. There is a woman, her grandson died because of this disease that is why she is trying to help others. She provided us with 5-6 ampules of “Neupogen” several times. There is another woman, her son is cured now, and she helps us financially as well”.

P., 40

Only three of the nine parents mentioned that they did not ask for support from Foundation, as their family members supported them.

“We can receive the drugs mainly free of charge (if the drugs are available) but we prefer to buy them on our own. We are very generous when it comes to drugs and the treatment of our son. My husband took a credit from the bank”.

P., 38

“We pay for some drugs that are not available in the hospital. I do not receive any financial support from charitable organizations; my parents help me a lot. I cannot say how much money exactly we spent on the child's treatment, as my father covered all these expenses”.

P., 32

Some of the mothers highlighted the importance of receiving financial support both for their children treatment/drugs, and for other expenditures (food, fare).

“...Sometimes it is very difficult to get the drugs, sometimes I do not have enough money. A financial support is also very important, not only money for drugs, but also for food and fare.”	P., 39
“I would like to receive money. I do not need any type of support. Only money”.	P., 40
“There are families that even do not have food for their children. We need financial resources”.	P., 39

### Conditions of the patient rooms

Pediatric patients from two of the three Oncology/Hematology hospitals reported that they were satisfied with the conditions in their patient rooms. The patients either had bathrooms with hot water in their rooms or in the department. They had separate beds for adolescents and supporters. The parents of those adolescents who received chemo treatment in the above mentioned hospitals agreed with what adolescents described.

“I like my patient room, as it is warm and I have a bathroom inside the room. Here each patient room has its own bathroom with hot water and a separate toilet. There are two separate beds for me and my mom.”	A., 19
“I am satisfied with the patient room, it is warm, and there are all necessary amenities. Each patient room has its own toilet and bathroom with hot water.”	P., 40

The adolescents who received their chemo treatment in another hospital reported that they were not satisfied with the conditions in their patient rooms, as mostly they shared the bed with their supporters, and did not have a separate bathroom. Moreover, pediatric patients from this hospital emphasized that there was no bathroom in the department either. All parents of those adolescents who received chemo treatment in this hospital confirmed their children’ opinions and described the conditions in patient rooms as “not comfortable”. Parents also

highlighted that one of the major problems related to conditions was the complete absence of bathrooms both in the patient rooms and in the department.

“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. We do not have a TV set and refrigerator in our room. My mom and I sleep on one bed; we do not have a toilet and a bathroom. For having a bath we leave the hospital and visit our relatives in Nor Hachn.”

A., 13

“...It is true we are in the hospital for about 40 days, and my son has not had a chance to take a bath. There are hospitals that have a bathroom and toilets, but here we do not have such facilities but God bless, let my child be healthy.”

P., 39

One adolescent and one parent from the same hospital who participated in this study mentioned that they were indifferent towards the conditions of the patient room.

“I cannot like or dislike my patient room, as it is a point of treatment for me. I should receive my treatment here, become cured and leave the patient room....Conditions in a patient room are not important, health is important.”

A., 17

“Currently I am not interested in my patient room. Obviously, conditions are not perfect, but it does not bother me, as I am focused on my son’s treatment and recovery.”

P., 39

All adolescents from all hospitals were satisfied with the temperature and cleanliness in the patient rooms. Mothers from all three hospitals mentioned that they clean their children’s rooms, while the rest of the department is cleaned by janitors. Two mothers from the same hospital highlighted that they brought additional means from home in order to clean their children’s rooms.

“It [patient room] is clean. Definitely the janitors clean the rooms, but after that we clean it again with antibacterial cleaners. If you ask other patients they will tell you that our patient room is number one for cleanliness.”

P., 38

“A janitor could not achieve perfect cleanliness. I clean our room; I even take all necessary

disinfectors from home for cleaning. I totally clean our patient room twice: when we enter the patient room and before leaving it.”

P., 32

All adolescents and their mothers who participated in the study mentioned that they did not have TV sets in their rooms. There was a refrigerator in the department and it was located in the kitchen.

In addition, adolescents mentioned that whether patients stayed alone in a patient room or shared it with others depended on patients’ health condition and the level of overcrowding in the department.

“My mom and I stay alone in our patient room, this is the doctor's order, as I have a low blood count, and she [treating doctor] does not want me to share the room with other patients not to be infected with a virus.”

A., 15

“We stay at this room alone, as currently there are several empty rooms. It is not comfortable to share the room with others.”

A., 14

“We do not have a separate bed and I have to sleep with my 17 -year -old son in one bed.”

P., 39

“There is a separate bed for my son. If there is no other patient I can sleep on the next bed. If there is a patient I sleep under my son's leg or sitting in the chair.”

P., 40

“As my son is the only child in the hospital that has both leukemia and speech disorder, we are allowed to stay in the patient room without other patients.”

P., 32

### Conditions of the department

All respondents had to stay in a hospital for each course of chemotherapy. Duration of one chemo course depended on the treatment protocol. All adolescents mentioned that there was a playroom in the department but there was no playground next to their hospitals. Almost half of the adolescents from this study indicated that they spent their leisure time in the playroom.

“I mostly spend my leisure time in the playroom..... There are no missing items in the playroom; we have everything handy. There is no playground, and we are not allowed to play outside”.

A., 15

“I like to play in the playroom.... We watch TV in the playroom very seldom, as we all [children] gather together and play a game. We have everything in our playroom..... There is no playground next to the hospital. Even if there was a playground, I would not be allowed to play there, as I have a very low white cell count”.

A., 13

All adolescents mentioned that there was a kitchen in the department, where mothers cook for them. All mothers found having the kitchen in the hospital useful. They also reported they had never received any food from the hospital. When asked about the food that children eat during the treatment, all mothers reported that their children followed a special diet which was the doctors' order.

“...We do not bring anything from home; my mom cooks fresh dishes here”.

A., 19

“... my child eats only the food which is prescribed by the doctors. He follows very strict diet, for example we should wash the fruits with boiled water and peel them, every day he should eat boiled beef. We learned that rabbit meat is useful for health and we tried to feed my son with it as well. Not every parent may afford this kind of diet. Following this diet is not our caprice, as the health and well-being of my son depends on it.”

P., 38

Several mothers from all three hospitals identified the need for having better conditions in the department and in the patient rooms. Some parents reported that they would like to see changes in the design of the oncology/hematology department. In order to protect their children from the viruses, parents suggested constructing a special corridor to separate oncology/hematology department from the rest of the hospital. One parent mentioned that patients' rooms need to be repaired.

“One of the problems in our hospital is that children and adults receive treatment in the same department. I think that special conditions should be ensured for children.”

P., 32

“Although conditions in our hospital are better compared to other hospitals, I would like to see improvements. One of the main problems in the hospital is that visitors may come from the street directly to the department, where children with leukemia and other types of cancer receive their treatment. It is not right, as they may bring lots of infections. I would suggest constructing a special corridor between the department and the rest of the hospital, where guests/visitors can meet their relatives without entering the department. In order to somehow mitigate this situation my husband buys lots of masks, overshoes and uniforms. We put it next to the main door and every visitor must wear them before entering patient rooms. But we do it by our means. And nobody will continue doin it after we leave.”

P., 38

“The patient rooms need to be repaired.”

P., 37

“I know that this is the only hospital of this scale in Armenia, yet the conditions are what they are. I know that they are constructing a new building. I hope that the new building will have better conditions.”

A., 15

Parents from two hospitals that participated in the study noted that there were no queues for the admission to the hospital. Several mothers mentioned that in case the department is unable to admit any more patients the head of the department would find a solution by adding more beds for children.

“There are no queues in the hospital. Even if there is no place at that moment in the hospital, they immediately put an additional bed for a child. They will find a solution.”

P., 38

Only one mother reported that there were queues in the hospital, where her child received chemotherapy treatment. She emphasized that they had to wait in a queue for tests (blood count, urine analysis, and ultrasound examination).

“I am arguing that my child should give tests without waiting in a queue, but other patients reply that they are cancer patients as well, why should they wait?”

P., 39

### Awareness of the treatment received

All adolescents were asked about whether they knew about the treatment they received. Almost every adolescent was aware that he/she received chemotherapy. All adolescents who participated in the study mentioned that they were satisfied with the treatment they receive in hospital, because they see changes, the results of treatment are good, the treatment is appropriate to their diagnosis, and they met patients in the hospital that had been cured.

“I am receiving chemotherapy: the first course of treatment has already finished. I am also receiving vitamins and antifungal drugs. I am satisfied with my treatment, as I see changes”.	A., 15
“I am receiving the treatment that is appropriate to my diagnosis”.	A., 17
“I am satisfied with the treatment I receive. First I received glucose and natrium chloride for cleaning the organism, then chemotherapy for cleaning the blood”	A., 14

### Best treatment from parents' perspective

When asked about the best treatment that adolescents can receive in Armenia, seven out of nine parents mentioned that they were satisfied with the treatment and considered it as the best possible treatment for their children.

“I think that in Armenia my son receives the best available treatment. I chose my son's doctor. The doctors from this hospital are more experienced, they were trained in Germany, and the conditions in this hospital are much better. Although, maybe there is another type of treatment that uses more sparing methods. I do not know.”	P., 32
“Before coming to this hospital I thought that I should give them a bribe. But we are here almost for 5 months and I have not paid anything. Definitely, I would say my “thank you” [will give money] at the end of the treatment, but the doctors do not expect anything from me. I am satisfied with the treatment. There was a child here, whose parents did not believe that he has leukemia and they checked the diagnosis in Israel. Israeli doctors confirmed the diagnosis and after this I trust local doctors even more”.	P., 39

Only two parents had doubts about the treatment their children received. They mentioned that they would like to have an opportunity to treat their children in Germany. One of the mothers said that everything is fine with her son's treatment in Armenia, but she would like him to receive the treatment abroad because of the severity of his disease.

"I do not know whether my son is receiving the best available treatment, I do not know. People told me that I should take my son to Germany, but it requires huge financial resources, that I do not have. This is a very dangerous illness, as it may seem to you that it has been treated, but it may come back in more adverse form. I think nothing is missing from his treatment, but the doctor does not give a guarantee, and I think that the doctors treating abroad will not give it as well. This is a very difficult question".

P., 39

"At the very beginning we wanted to go to Germany, but we understood that this is not a solution to our problem, because only one of the parents could accompany the child. Imagine the situation of a parent who is on his/her own in Germany, without relatives, friends. On the other hand, imagine the poor situation of a parent who stays in Armenia. My husband wanted to accompany my son, but I cannot live without him. Thus we decided to stay."

P., 38

All parents, who participated in this study asked about what palliative care means, and none of them were aware of the term.

## **Physical domain**

### Pain assessment and control

All pediatric cancer patients reported that they did not experience pain at the time of the interviews. Almost half of the adolescents mentioned that before being admitted to the hospital for the first time they experienced pain in different parts of their body (continuous bad headaches, pain in legs, knees, and jaw). Parents of these adolescents reported that after receiving chemotherapy the pain was successfully managed.

"When I entered the hospital I had a pain in my legs, but the doctor put gypsum on my leg in order to alleviate the pain. After gypsum the pain has gone."

A., 13

“When I first entered the hospital I had low blood count, I had bad, continuous headaches. I was very weak and had pain in my legs.”

A., 15

Some adolescents mentioned that during the treatment they experienced pain mainly because of the invasive, painful medical procedures (bone marrow biopsies, lumbar punctures, vein injections, etc.). Only one of the adolescents that participated in the study experienced pain because of the cancer itself.

“I have pain in my veins, when the nurse is doing an injection. Sometimes I am crying because of this pain”.

A., 14

“Now he has pain in veins and cries very often, he cannot endure injections anymore. He [the child] has become very sensitive.”

P., 34

“I feel pain when the doctors make a lumbar puncture. Once they tried 7 needles and only after that they managed to do a lumbar puncture. But even after that I was able to reach my room on my own”.

A., 17

“He has pain in his back, because of a lumbar puncture. But he endures it and refuses to be anaesthetized, as he does not like when we treat him as a patient”.

P., 39

“Sometimes I have weak pain in my legs, but this is because I am lying all the time”.

A., 14

“I have a horrible acute pain in my jaw that spreads to my ear and head”.

A., 15

All adolescents that participated in the study and experienced pain during the treatment reported that they received adequate pain control. The same opinion was shared by mothers of those adolescents who reported having pain during medical procedures. Only one adolescent mentioned that sometimes anesthesia does not work.

“...They always do anesthesia before lumbar puncture, but sometimes it does not work”.

A., 17

“...I received pain killers for my injured knee. After 4 courses of chemotherapy I underwent a knee surgery. I received pain killers after orthopedic surgery as well.”

A., 19

“... If my child says that he is in pain, the nurse comes immediately and gives him an injection.”  
P., 34

### Treatment-related symptoms management

Most of the adolescents noted that after receiving chemotherapy they experienced weakness (fatigue), nausea, and loss of appetite. Nearly half of the adolescents who participated in the study reported that after receiving chemo drugs they had allergic reactions (skin rash and itching). Mothers who participated in the study reported nausea as one of the main side effects that bothered their children. Among other side effects mothers listed hair loss, problems with intestines, gallbladder, and teeth, as well as hypertension, and stomatitis.

“.... I do not have side effects because of drugs”.  
A., 12  
“After drugs I have spots on my face. The nurse makes an injection, and it [allergy] goes away”.  
A., 15  
“I have allergy, thus after drugs I have spots on my face. The nurses do an injection, and it [allergy] goes away. I do not have negative side effects. My mom has informed the doctor about my allergy, so the doctor stays with us to see the reaction of the drugs”.  
A., 15  
“Mostly after taking drugs my son suffers from hypertension.”  
P., 39  
“My daughter suffers from hair loss. In the mornings I wake up earlier to collect the hair from her pillow for not stressing her even more.”  
P., 32

Vast majority of both adolescents and parents reported that physicians managed almost all side effects that occurred after receiving chemo treatment. Both mothers and adolescents reported that the only uncontrolled side effect was fatigue (weakness).

“For preventing nausea, before taking chemotherapy the nurses give him an injection, sometimes after chemotherapy as well.”  
P., 39  
“All side effects are controlled. Though sometimes we do not take the drugs for side effects that

doctors prescribe, as they are from China, and we buy the same drugs made in Europe. Once we paid 100 \$ for anti-nausea drug.”	P., 38
“... Currently he [adolescent] is receiving chemotherapy and drugs for hypertension. Because of the chemotherapy his [sons] teeth are broken, he is taking calcium for that as well.”	P., 39
“I receive medication for nausea and vomiting, but there is no drug for fatigue. I should wait till it passes”.	A., 19

The majority of adolescents reported that side effects do not bother them, as they last only several days. Only one of the respondents mentioned that because of the weakness he did not want to meet his friends in the hospital.

“After chemotherapy I suffer from nausea, weakness, and poor appetite for several days. I receive drugs for nausea but I do not receive drugs for weakness and poor appetite. These side effects do not influence me, as they [side effects] last only several days. After several days I recover and forget about side effects.”	A., 19
“I do not have mood to host my friends in the hospital because of my weakness. I would like them to see me active, rather than passive and weak.”	A., 13

## **Psychological domain**

### Adolescents’ understanding of cancer diagnosis

All adolescents were aware about their diagnosis and understood the necessity of taking chemo drugs in order to be cured. Despite this, the vast majority of them did not adequately understand the seriousness of their conditions. Some of the respondents were not interested in learning more about their diagnosis. None of the adolescents who participated in the study mentioned about life-threatening nature of their condition.

“I know that I have lymphoma, but I cannot explain what it means”.

A., 13

“I have knee sarcoma. I was cutting the wood in the yard and suddenly I hit my leg with an axe. Because of this incident I was diagnosed with cancer”.

A., 19

“This disease is blood leukemia. I cannot explain what it means, as I do not know much about this. I am not interested in this disease, but my mom told me that I have to know about my diagnosis, in case if I hear about it from others. She said that my disease is treatable”.

A., 14

“Leukemia, it is a blood disease. I do not want to know more about this diagnosis; I do not even search in the internet. My parents do not speak about my diagnosis. They only ask about what I would like to eat”.

A., 12

When asked about who told the child about diagnosis and how it was explained to him/her, all parents reported that either they told about diagnosis in a very superficial manner or did not talk about diagnosis at all. Parents explained this approach by saying that they did not want to make their child’s life even more complicated.

“I spoke to my son about his diagnosis. I did not discuss the whole situation with him. I just briefly explained that he has a disease that is treatable and everything will be fine. I am trying not to make his life more difficult.”

P., 39

“I cannot be completely sincere with her [child] and this is mutual....The child was in the patient room, when I asked the doctor about the diagnosis. She [daughter] understood some things at that point..... She is a 15- year-old girl, and she has a serious illness at her age. Today is her birthday. No hospitals, no doctors, no drugs before that, and suddenly a serious illness.”

P., 37

“My son is aware of his diagnosis. He knows that he has acute lymphoblastic leukemia, but he does not know that it is the same as blood cancer. Once my mother-in-law was writing a letter to the First Lady for help, and my son asked her to read the letter for him. Unwittingly, my mother-in-law pronounced "blood cancer". My son became pale, and started to shout “I have lymphoblastic leukemia, not blood cancer”. I told him that his grandmother is an old person and she confused the terms.”

P., 39

### Adolescents' acceptance of long-term illness and confinement to the hospital

Almost half of the adolescents described that they have experienced fear, isolation, distress and sadness when they were first admitted to the hospital. The most common reasons that helped adolescents' to gradually accept their illness and confinement to the hospital were seeing patients who have been cured and discussing the disease with their treating doctor.

"I was afraid when I first entered the hospital, but now I have got used to the situation. It is almost 40 days that we have been in the hospital. When I see the patients that have been cured, I accept my condition".

A., 15

"At the very beginning I was very sad. I was not speaking to anyone. Gradually I was getting used to the situation..... When I have a question related to my diagnosis or analysis, I can ask my treating doctor. She explains everything and it helps a lot".

A., 19

### Fears and anxiety about the treatment

The vast majority of adolescents reported that they did not experience fear or anxiety related to treatment. Three out of eight respondents mentioned that they were mainly concerned with the daily problems of their family members.

"I have concerns about leaving and coming back to the hospital every time. For the first course of treatment we should stay at the hospital, but for the next courses we should come to the hospital twice a week. We live in Gyumri and it is difficult to travel several times a week. My dad is trying to find a solution for us to stay in Yerevan, maybe he [dad] will rent an apartment. Only this bothers me."

A., 15

"I do not have any fear or anxiety about my treatment as God heals me by the doctor's hands."

A., 17

"I will be very happy if someone helps my family while I am sick. Before (illness) I took care for my family, I sold fruits and vegetables."

A., 19

### Psychological services for adolescents

Psychological service was available only in two out of three oncology/hematology hospitals where interviews were conducted. Two psychologists and one teacher worked in one hospital and one psychologist worked in another hospital. Both the mother and the adolescent from the hospital where the psychological service was not available reported that they would like to receive psychological support during the treatment.

“I would like to meet a psychologist here, as there are specific problems that I would like to share with her”.

A., 15

There were no separate rooms for individual psychological counseling in the hospitals, and meetings with psychologists were held in playrooms. In both hospitals playrooms were open from 9:00 am to 16:00 pm. All participants mentioned that they met psychologist in their patient rooms when they entered the hospital for the first time. Afterwards, they did not have regular individual counseling with psychologists. Two older adolescents who participated in the study noted that either psychologists did not visit them, or had a very quick conversation, as psychologists were busy in the playroom with younger kids. Almost half of the adolescents mentioned that even though they were satisfied with the meetings with psychologist in the playroom, they would like to have individual meetings with them.

“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”.

A., 15

“I feel relaxed when I speak to a psychologist.”

A., 15

“Our psychologist visits me frequently. Yesterday she gave me an assignment to draw white blood cells, as my analysis showed that I had a low blood count. She said that the more I draw the higher my blood cell count will be”.

A., 13

“We have a psychologist here. She mostly works with kids. I have never had individual meetings

with a psychologist; she does not visit me frequently....If I have something to share I share it with my friends... friends from the hospital”.	A., 19
“Today I just met a psychologist, but we did not talk much”.	A., 14
“It is very important for my child to receive psychological support in the hospital, but he does not get it.”	P., 32

Two mothers reported that either psychologist refused to work with their child, or their child was not interested in meetings with psychologists.

“There is a psychologist in the ward, but my son does not want to speak to her, as he has all the necessary gadgets in his room and likes to spend time alone. When my son feels disappointed or anxious he prefers to talk to his treating doctor.	P., 38
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#### Psychological services for parents

Many mothers who participated in the study highlighted the need for receiving psychological support while being in the hospital. They stressed that psychological support would be particularly helpful when their child had been diagnosed with cancer and admitted to the hospital for the first time.

“... It was awful. It was a huge psychological problem for me. At the very beginning I was crying all the time. When the doctors tried to speak to me I was crying. Afterwards, I got used to this new situation. I needed time.”	P., 32
“The first three days in the hospital were awful for me, as my son shouted at me and wanted me to leave his patient room, because it was my idea to do a blood test. Imagine my situation; I was pregnant, just learned about the diagnosis, that nightmare and his emotional reaction to it.”	P., 38
“If you are stressed, it can destroy you. It is true that the treatment still works, but as a parent you cannot do anything for your child.”	P., 39
“We need psychological help badly to share, to talk, to understand something.”	P., 37

Some of the mothers who participated in the study shared their husbands' emotional reaction to their children's diagnosis. Mothers mentioned that their husbands also were in need of psychological support when they had been told about their child's diagnosis.

<p>“At the very beginning when we were told that our son has leukemia, my husband had psychological problems”</p>	P., 32
<p>“Maybe you would not believe me but when we were admitted to the hospital for the first time, my husband could not sleep for a week. I thought that he is going to lose his mind.”</p>	P., 38

### **Social domain**

#### Communication with health care providers

All adolescents who participated in the study described their relationship with physicians and nurses as “very open”, “good” and “close”. Moreover, all participants reported that doctors and nurses were very careful and visited them frequently for making an injection, measuring temperature or just learning about their health. Two adolescents mentioned that they felt confident to approach their doctors if they had a question or felt disappointed because of the test results.

<p>“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”.</p>	A., 15
<p>“They [doctors] are very careful and all they are saying is “jan, jan [dear]”. We are very close”.</p>	A., 12
<p>“Twice a day my doctor visits me, nurses visit me more often. If I am disappointed with my tests, I call my doctor and she explains it to me”.</p>	A., 19

“Nurses mostly visit me to check my health state-temperature, injections. They visit me once per hour”.

A., 14

The parents mentioned that when it comes to discussing the diagnosis and treatment for their children, they first talk to their treating doctors. The parents from all hospitals described their relationship with health care providers as “supportive”, “attentive”, “open”, “close”, and “trustworthy”. Some parents said that even when their other children had health problems, they could refer to their children’s doctor, because they trust them a lot and consider them as their family doctors.

“When we are at home and my son feels bad, for example has flu or temperature, I call his doctor. I do not call for a pediatrician; as they may not understand my son’s condition. For example some pediatricians prescribe “Nurofen”, but this drug is forbidden for my son.”

P., 32

“I would definitely speak to my son's treating doctor. She became our family doctor and even when something happens to my other children, I call her.”

P., 38

“We are from Sisian...Our treating doctor told that irrespectively of the time of the day, we can call her. Last time when we were at home my son had high temperature. I called the doctor even though it was very late at night. She ordered to take the child back to the hospital. It was 4 AM in the morning when we entered the hospital, and our doctor was waiting for us.”

P., 39

“Even head of the department visits us frequently only to talk to my son. Once he [head of department] told that he was so proud of my son, as he knew his protocol better than medical students that passed their internship in the department. He advised my son to become an oncologist.”

P., 39

One parent reported that she had conflicts with the health care provider during her child’s treatment.

“I am very demanding person especially when the issue refers to my son. Once the nurse threwed the needle on the floor then took it from the floor and wanted to do an injection.

Although the needle was in a box, it disturbed me. Once I had a conflict with the senior nurse. I was asking for something and she replied grudgingly. I told her that she must treat me normally, as I am not obliged to her and she is not obliged to me. She [senior nurse] must do her job. It is not my business that she may have problems at home. I have my own problems and I am suffering a lot.”

P., 32

Almost all parents who participated in the study mentioned that the doctors discussed with them the diagnosis of their children without going into details. Majority of parents reported that they received sufficient information on their children diagnosis. Yet one parent reported that she was very anxious about harmful effect of chemo drugs on her son’s speech, as the child was born with speech disorder.

“The doctors try to not involve us in the treatment process, because if we know much, we disturb them. The doctors say that we do not know much about the disease; we just read something from the books or in the internet and become scared, as everything seems very dangerous..... When our treating doctor is on duty, my husband comes from work and asks questions. It is like a torture for her.

P., 38

“... my son is the only child in the hospital who is diagnosed with both leukemia and speech disorder. At the very beginning I was asking about whether chemotherapy might harm my son's speech. And the doctors asked "What is most important for you, your son's speech or his life"? Both are very important to me. I am fighting since he was 2 years old and I am going to fight for his health till the end. I was asking about the drugs they injected and obviously they did not like it. Once the doctor told me that it is impossible for me to know all the drugs.”

P., 32

### Communication with family members

All participants of the study were asked about support they received from family members. Although the support that adolescent’s were getting extended beyond the family, their mothers' role was prominent. All of the adolescents stressed that during the whole course of treatment mothers were the main supporters, they stayed in hospitals and took care of them, and they shared their concerns and thoughts with their mothers. One adolescent mentioned that she

cannot speak to her mother about her concerns and fears related to the disease, as her mother cries all the time when talking about the disease. Three adolescents mentioned that fathers mainly solved problems related to drugs, food and place for living while receiving treatment in Yerevan. Two adolescents mentioned that grandmothers helped them by taking care of their brothers and sisters at home.

“My family makes me happy. I share my thoughts with my mom. When I am disappointed, I talk to her [mom].”

A., 13

“My father died. I am very close with my mom. She supports me a lot.”

A., 14

“With my mom I cannot speak at all. I am crying in the evenings, when she [mom] is in the kitchen. Last evening I was crying again, because my college friends called me.”

A., 15

“Every day my father visits me in the hospital and brings food. He does not allow me to eat food that my guests bring. He should be sure that the food I eat is safe.”

A., 14

Mothers reported that they took care of their children in hospitals alone, though other family members supported them either financially or took care of their other children.

“I take care of my child alone, but my mother-in-law helps me by taking care of my other four sons. Though we are apart, I know that someone takes care of them.”

P., 39

“Only I can take care of my child, I do not trust anyone. My father helps me a lot. I have a very good mother but I do not feel a strong connection with her. I have a very close relationship with my father; he supports me both financially and psychologically.”

P., 32

Only one mother reported lack of understanding from relatives.

“It is very difficult with my other relatives - mother-in-law, father -in-law. They live next to me and we argue all the time. When they are ill, have flu, they want to visit my son, kiss him, and I do not let them. This could lead to a conflict. I would like my relatives to understand me better. Sometimes they may scold me for not cleaning my house. But I do not have time for that. My child’s well-being is a priority for me”.

P.,32

Communications with friends and school mates

All participants who studied at school or college at the time of being diagnosed reported that they regretted the disruption of school, because they missed their schoolmates.

“I regret that I cannot go to school and see my friends [started to cry].”	A., 15
“... I am missing my school. I do not like school, but it is better to go to school rather than to stay in hospital.”	A., 12
“I regret the disruption of school, I miss my friends.”	A., 13

Almost half of the participants who studied at school or college at the time of being diagnosed mentioned that they experienced anxiety because of the exams they should pass.

“...I ask my friends to bring the copies of our lectures to the hospital where I can study. At the end of the year I have exams, I would like to get prepared for the exams.”	A., 15
“... I am anxious because next year I am to take my exams, but I am not ready for them. Now I am in the 8 <sup>th</sup> grade, in 9 <sup>th</sup> grade I should pass the exam.”	A., 13

Vast majority of adolescents who participated in this study highlighted that they received both financial and psychological support from schoolmates.

“...I have a friend in school, and during the whole semester he wrote all my homework and even exams. Sometimes he stays at school after classes and writes my exams..... I am missing my school.”	A., 12
“My college friends and neighbors gathered money for my treatment. They are next to me both financially and psychologically. They always visit me. They give me energy and psychological support to fight.”	A., 14
“Once my school mates and other students in the school gathered money for us. I felt good. The director invited my mom to the school and gave her money. Yet I have not expected anything	

from them.”

A., 13

Almost half of the adolescents who participated in the study expressed willingness to study in the hospital, to get prepared for the exams. Only one of the adolescents reported that they had a teacher in the hospital and that she assigned him tasks to do.

“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. Now I follow my grades by dasaran.am site. My teachers just gave the grades and helped me to graduate from the school.”

A., 15

“I studied till the 9<sup>th</sup> grade, and then I went to a college. Now I am a second year college student in computer programming department. It is important for me to continue my education here, as I do not know much and can forget what I have already learned. But for that I need a tutor.”

A., 17

“...Now I am in the 8<sup>th</sup> grade, in 9<sup>th</sup> grade I should pass the exam, but I cannot. I would like to study in the hospital to be prepared for the exams. We have a teacher in the hospital, she gives assignments to me and I am trying to do them. But it is not enough, as we do not cover all disciplines.”

A., 13

## **Spiritual domain**

### Cancer as a life-changing event

Significant majority of adolescents who participated in the study recognized their diagnosis as a life-challenging and critical event. They described that after being diagnosed with cancer they felt that they were different from their friends, and that they matured faster than their peers. Some participants considered cancer as something that was sent to them to make change in their lives, to give an opportunity to think about their dreams, to take some steps for their future. Only one participant mentioned that cancer did not influence his life in any way.

<p>“Before the diagnosis I used to think only about the current point in time, but now I am thinking about larger things. I am rather old for my age [started to cry]”.</p>	A., 15
<p>“Before coming here my thinking was superficial, but now I am on the right direction. Life has changed. When I am at home, and meet with my friends, I feel the difference. Now I am different, I have a different experience. Friends from hospital understand me better, they understand my mood”.</p>	A., 19
<p>“For sure God has a deal with me, as he has given me this illness. If God did not love me I would already be dead. God helps me to pull myself together”.</p>	A., 17
<p>“I think that this is a specific period in my life. And I was given this time to think about myself. I should think about my dreams and what kind of steps should I do to fulfill my dreams. I should understand how I can spend my time not to regret it in the future. I should think about steps that I should take to visit France”.</p>	A., 14

When asked about how the diagnosis and the treatment of their children affected parents’ life, almost every participant described that it was most “horrible”, “unbelievable”, “heart breaking”, and “life changing” event of their life. One of the mothers mentioned that her sons’ diagnosis changed her attitude towards other people and made her more optimistic, while another one described that her son’s diagnosis made her become a colder person. Almost all mothers who participated in the study reported that they experienced strong belief in God.

<p>“I cannot describe what it looks like, when a mother learns about her child's diagnosis. It is indescribable.....My faith helps me to be strong. When I am alone, I argue with God why me, why my son? I brought up my son alone, with great difficulties, why my son?”</p>	P., 34
<p>«To tell honestly, this illness is something horrible. My father-in-law died because of the blood cancer. I believe that God has given us life and he will take it from us. This fact helps me to find peace inside”.</p>	P., 39
<p>“It is very heart breaking when I see my son lying on the bed. Sometimes I want to cry, but I</p>	

swearing not to cry in my son's presence".

P., 40

"My son's illness changed my life. Now I am more polite with other people, even when they hurt me. I became an optimist. Now I love people more, as I remember that period in my life, when everyone was next to me with great willingness to support. Now I must give them back that attitude. There is something educational in it. We become better people. If you pass through this you cannot be the same person".

P., 38

"After diagnosis I became a very "cold" person, I do not have strong emotions, I became indifferent towards lots of things, I do not even cry when someone dies. My life has been changes since my child has been diagnosed. Now I do not have my own life, emotions, wishes, feelings, everything is connected with my son".

P., 32

"My life has been changed emotionally, financially, and physically. I do not feel myself, my life. There is no life for me till he is cured. I am not interested in anything, I am indifferent. I am just surviving for him".

P., 39

### Special connection with God

The majority of adolescents mentioned that they read the "The New Testament" in their patient rooms with their mothers. Three participants mentioned that they started reading it after the admission to the hospital. Some adolescents said that they reconsidered their condition within the context of their faith.

"I read "New Testament" with my mom in our patient room ...The most important thing for me is my relationship with God, if I have a good relationship with God, everything will be good".

A., 17

"Here in the hospital I read "New Testament". I have never read it before; I started reading it in the hospital. During these 12 courses of my treatment I have read "New Testament" several times. I deeply believe in God".

A., 19

"If you have this disease you should trust God and you will not suffer."

A., 17

## DISCUSSION

To our knowledge this is the first study that aimed to assess the palliative needs of adolescents diagnosed with cancer and their parents in Armenia.

Our study results revealed that the financial aspect of adolescents' care was challenging throughout the treatment continuum. Although the care for pediatric oncology patients in Armenia is free,<sup>40</sup> most of the parents paid for the drugs for treatment. In Armenia the treatment of these patients is carried out according to the international protocols which require expensive drugs that are not covered by the Government. Hence parents have to carry the financial burden if they want their children to be treated with these drugs. Similar results were reported by the studies conducted in several low-and-middle-income countries.<sup>41-43</sup> According to the results of the study by Ghatak at al., families could spend up to seven times of their monthly income over a period of 1 month on chemo treatment for their child with cancer.<sup>43</sup> Despite financial aid from various sources, for such families nonmedical costs (living costs, transport cost, cost for food) were 2.5 times higher than their average per capita income.<sup>43,44</sup> Furthermore, our study showed that some of the chemotherapy drugs were not available in Armenian pharmaceutical market and parents had to order them from abroad using their own channels. Yet importing drugs from abroad is time consuming and might lead to delays in treatment. The financial support currently provided by "Grand Life" charitable foundation to these families cannot be seen as a sustainable solution, and therefore designing the financial mechanisms which would substantially reduce the financial risks for these families seems imperative to assure high quality uninterrupted treatment for pediatric oncology patients in Armenia.

The physical conditions of the facilities where our respondents were treated varied substantially. The participants staying in two of the hospitals included in the study were satisfied

with the beds, bathrooms, toilets, and kitchens in the oncology departments. The conditions in the third hospital were less than satisfactory with both children and their parents complaining about having to share the bed with caregivers, as well as having bathrooms neither in the patient rooms, nor in the department. In some of the hospitals providing care to both adult and pediatric cancer patients special efforts have been made to renovate pediatric departments. Yet it has not been done in all hospitals, and overall, the conditions in many facilities in Armenia providing oncological treatment, remain poor. A study which was conducted in Armenia in 2013 to assess the experiences of breast cancer patients with chemotherapy treatment reported the absence of basic conditions in the largest public oncology hospital.<sup>45</sup> The national pediatric palliative care needs assessment conducted in Ireland in 2005 highlighted inappropriate physical conditions in hospital settings (e.g. no privacy or comfort, dirty toilets, dirty laundry and parents sleeping on a fold-up bed or chair).<sup>29</sup> The same source emphasized that children's wards were not always suitable for adolescent care.<sup>29</sup>

Our study findings also highlighted that although adolescents experienced pain mainly because of the invasive medical procedures such as bone marrow biopsies, lumbar punctures, vein injections, in the hospital settings they received adequate pain control. Almost all adolescents in our study experienced weakness (fatigue), nausea, loss of appetite, loss of hair, and allergic reactions in the process of treatment. Nausea had been reported as the major side-effect that was successfully controlled, while fatigue was the most uncontrolled side effect. These findings are in line with those of previous studies, according to which fatigue was the most frequently reported symptom, and many oncology patients with fatigue suffered a great deal of it.<sup>15,21</sup>

Our study showed that upon the admission to the hospital many adolescents and their caregivers experienced fear, isolation, distress and sadness. Similar findings have been reported by many authors who provide evidence that parents of children with life-threatening illness are at elevated risk of distress reactions, involving symptoms of acute stress disorder, depression and anxiety.<sup>23,24,46,47</sup> In a Swedish study, a notable percentage of parents of children with cancer who relapsed had symptoms similar to those of posttraumatic stress disorder.<sup>48</sup>

Our study results revealed that although, psychological service was available in two out of three oncology/hematology hospitals, neither parents nor adolescents received individual psychological counseling. There were no separate rooms for individual meetings with psychologists in any of the hospitals. On the other hand, professional competences of some of the psychologists, who worked mainly with the younger children, were not sufficient for providing age-appropriate counseling for adolescents and their parents. Literature highlights that adolescence is a very unique time of the lifespan, and cancer seriously challenges an adolescent's autonomy and independence, sense of self-esteem, leading to feelings of loss of control at a time when self-image is pivotal to normal development.<sup>24,49</sup> In order to meet these unique needs individual psychological meetings are required. Study conducted by Smith et al. highlighted that adolescents and young adults with cancer had unmet needs for mental health professional services.<sup>50</sup>

In our study parents of adolescents diagnosed with cancer were also in need of psychological support which they did not receive.

Many studies have shown that parents confronted with the diagnosis of childhood cancer have experienced anxiety, depression, insomnia (sleep disturbances), yet most of them have not received adequate psychosocial support.<sup>24,51</sup> Hopia et al. notes that when a child has a serious

illness oftentimes the whole family is “ill” and the overall health of the family becomes vulnerable.<sup>52</sup> Another study which focused on mothers’ needs while facing the difficulties of having a child with cancer, pointed out that it was important for mothers to have a place where they could feel comforted in the moments of fragility.<sup>26</sup> Thus pediatric palliative care, as opposed to other models of care, should be designed to treat the whole family and not just the child.

The important finding that emerged in this investigation was that the adolescents who studied at school or college at the time of being diagnosed regretted the disruption of school, as well as experienced anxiety because of the exams they should pass. Several hematology-oncology clinics in the USA that provide pediatric palliative care for children with cancer offer school services to all pediatric patients during both inpatient hospital stays and while living in the community as an outpatient.<sup>53</sup> School services include several programming options- schooling at hospital settings, homebound schooling, as well as virtual schooling.<sup>53</sup> Moreover, school services support children to return to school as soon as they can after they are diagnosed with cancer.<sup>54</sup> Such services are currently not available for adolescents with cancer in Armenia.

Our study results highlighted that mothers were the main supporters of the adolescents with cancer, while fathers mainly solved the problems related to obtaining the drugs, food, and for those families from Armenian provinces, place to stay in Yerevan. Grandmothers helped adolescents with cancer by taking care of their healthy siblings at home. Our results indicate that all family members get involved in the care of their patients, yet everyone takes their specific role and responsibility. Our findings are congruent with those in international literature.<sup>24,25,55-58</sup> Generally, families alter their roles, responsibilities, and family functions to accommodate the child with cancer.<sup>55</sup> Family structure of extremely high adaptability and cohesion may be more

functional in the specific context of childhood cancer.<sup>56</sup> Family's primary adjustment to child's illness may cause changes in the family structure, family rules, and roles.<sup>57</sup> Yet according to another study, if adaptability becomes a long-term, chronic state of constantly fluctuating rules and roles in family, it may lead to harmful and negative effect on the family members, as well as become a reason for marital distress.<sup>25,58</sup>

In our study the majority of mothers and adolescents diagnosed with cancer were satisfied with their communication with physicians and nurses and described it as very open and close. Some of the mothers noted that although physicians did not discuss the diagnosis of their child in details, they were satisfied with the information provided. Yet there were also cases when parents perceived an unwillingness of physicians to discuss their child's care, particularly where it referred to getting more precise information on the drugs that were used in chemo treatment for their child, including the types of drugs, and their influence on child's mental and speech abilities. This situation may be explained by the fact that sometimes physicians do not feel themselves confident enough to communicate with parents due to prognostic uncertainty of child's treatment. The literature emphasizes that sometimes physicians may feel discomfort with the intense emotions displayed by parents or may feel guilty or inadequate regarding their inability to cure the child.<sup>59,60</sup>

We found that all adolescents were aware about their diagnosis, although their understanding of the diagnosis was superficial. None of the adolescents considered their diagnosis as life-threatening. Some of them were not interested in learning more about their diagnosis. Yet our results contradict those obtained in the study conducted with the group of Australian young people with cancer, which showed that almost all of adolescents wanted to be

informed about "bad news," such as treatment is ineffective, prognosis is poor, death is imminent.<sup>62</sup>

Mothers were reluctant to openly discuss the diagnosis and treatment prognosis with their children in order not to “complicate their children’s life even further”. We explain it by a general perception that exists in a society that children should not be aware of their diagnosis. Yet the literature states that the child should be listened and properly informed about his/her illness with due consideration to his/her wishes, age and ability to understand (reference). Another reason that might lead to this is parents' unrealistic beliefs about the treatment outcomes for their children. A study that assessed understanding of likelihood of cure and functional outcome among parents of children with cancer showed that the majority of parents are overly optimistic about chances of cure.<sup>60</sup>

The study revealed that both mothers and their children considered cancer diagnosis as a life-changing event. The vast majority of adolescents stressed that they started thinking about their connection with God after getting into hospital. Many adolescents started to read the “The New Testament” with their mothers and felt that it was a unique connection with God that helped them to cope with cancer. Literature shows that spirituality has a positive influence on cancer patient’s wellbeing, as it is a source of comfort and hope contributing to a better acceptance of the disease.<sup>26,63–65</sup>

### *Study Strengths and Limitations*

To our knowledge, this is the first study about the needs of adolescents diagnosed with cancer and their parents in Armenia. The qualitative design of this study and the use of the PPC’s framework of palliative care helped to collect rich and detailed information on most of the study topics, which would not be achieved had we chosen the quantitative methods to answer the

research questions. The triangulation of findings through parents and adolescents, as well as interviewing participants from several hospitals added credibility to the study findings.

Several study limitations merit attention. One of the main limitations of the study was the reluctance of some of the parents to openly share their thoughts related to communication with health care providers. In order to partially address this limitation several interviews were conducted at participants' home. Another limitation was the absence of statistical information and the lack of literature published on this topic in Armenia previously, which could guide the development of the study and support its findings. And finally, only patients receiving hospital care were included in the study.

### Conclusions

This study is the first qualitative study that assessed the needs of the adolescents diagnosed with cancer and their parents in Armenia. The most important challenges that were revealed by participants included financial burden of the treatment, the unavailability of certain 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.

### Recommendations

We hope that this assessment will help to direct greater attention to the needs of adolescents diagnosed with cancer and their parents. Based on the analysis of the study findings, we suggest the following steps that should be urgently taken to improve the provision of pediatric palliative care in Armenia. First, we suggest revisiting the existing mechanisms of financing the treatment of pediatric cancer patients in Armenia to ensure a comprehensive coverage of the treatment according to internationally endorsed treatment protocols. Second,

finances should be sought to renovate facilities where children receive treatment to ensure minimum standards for receiving prolonged hospital care, as well as to satisfy specific needs that such patients and their caregivers might have, including separating pediatric departments from the rest of the hospital, allocating space for individual meetings with psychologists, and designing playgrounds next to the hospitals. Third, we suggest helping adolescents to continue their studies during the treatment course within the context of their health needs through distance schooling (i.e., via Internet) and/or visits from instructors. Finally, we suggest further exploration of the pediatric palliative care in Armenia through the lens of healthcare providers to understand their needs and challenges associated with the provision of care to pediatric patients with cancer and their families.

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## APPENDICIES

### Appendix 1. Interview guide for adolescents with cancer (English version)

ID:

Date:

Place:

Time:

Interviewer:

Provide assent form.

Introduction of the topic: *As I have already mentioned I would like to know more about the needs of adolescents who are receiving treatment in this hospital, as well as the needs of their parents. I would kindly ask you to share your personal experience with me which will help us to find a way to improve the care you and your parents receive.*

*Can you tell me about yourself? How do you feel today? How old are you? Where are you from? With whom from family members are you staying in this hospital?*

#### **Physical Domain: Hospital services, treatment, control of pain and side-effects.**

##### ***Hospital services/Ward conditions***

1. Do you stay at the hospital for the whole course of treatment? (*Probe: Every day after receiving your treatment do you leave the hospital and come back for the next day?*)
2. How do you like your patient room? Is it warm enough in your room? (If no-What do you use to make it warmer?) Do you stay in your room alone or share it with other patients? What do you have in your room?
  - TV
  - Refrigerator
  - Comfortable bed
  - Separate bed for supporter (parent/caregiver)
  - Separate toilet
  - Separate bathroom
3. Do you eat the foods that you like while in the hospital? (*Probe: What is your favorite dish?*) Do you have a kitchen in the ward? Does your mom/caregiver cook there?

*Now I would like to know how you spend your leisure time.*

4. What do you do in the hospital when you have free time? Do you watch TV? (*Probe: Is it free or you should put the coin to make it work? How many channels does it broadcast? Do you have favorite TV programs that you watch frequently here?*) Do you have a playroom? (*Probe: Do you like playing there? What do you like the most in the playroom? Is there something that you would like to have in playroom?*) Do you have a playground at the hospital? Do you have any hobby? Are you able to continue your hobby activities in the hospital?

##### ***Communication with nurses/doctors/ the attitude of providers***

5. How do physicians/nurses treat you? (*Probe: Do you think that physician(s) understand what is going on with you? Are they kind to you? Do you like talking to them?*)

6. How often do nurses/doctors visit you and for what? (*Probe: for a procedure, just to chat, to measure your temperature, etc.*).

### ***Treatment, control of pain and side-effects***

7. What kind of disease do you have? (*Probe: Where do you have pain?*)
8. Could you describe the treatment (medications) that are you currently using? Are you satisfied with the treatment? (*Probe: Do you have feelings of anger or fear about your treatment? If yes, can you tell me about them?*)
9. Could you describe the side effects because of medications and treatments? How side effects are controlled? How is it affecting you and /or your family?
10. Do you experience pain? How much pain do you experience? \_\_\_\_\_ (“0–10 Numeric Pain Rating Scale” Appendix 3). How pain is controlled? Are you satisfied with pain control received?

### **Psychosocial and spiritual Domains**

#### ***Family members/relatives***

11. How would you describe the support that you receive from your family members? (*Probe: Are you talking to them about your feelings? Do they help you to carry on? Do they comfort you when you feel sad about your disease?*)
12. What kind of support would you like to receive from them? (*Probe: What would you like them to do for you?*)

#### ***Friends***

13. How would you describe the support that you get from your friends? (*Probe: How many close friends do you have? How often do your friends visit you?*)
14. What kind of support would you like to receive from friends? (*Probe: What would you like them to do for you?*)

#### ***School***

15. Do you go to school? If no-How do you feel about disruption of school? Would you like to continue your studies at hospital/home? If yes-How would you want it to be arranged?

#### ***Support from others***

16. What kind of help/support do you currently receive? (*Probe: Do you have psychological service, teacher in the ward, etc.?*). If yes- Are you satisfied with these services?). If no - What each of these individuals/services could provide you? (*Probe: What kind of help would you like to receive from psychological services, from social workers?*)

#### ***Spiritual aspect***

17. What makes you feel good or happy? Do you have any fears about your disease? What worries you the most? (*Probe: What has bothered you the most while you have been sick?*)
18. People respond to being ill in different ways. I wonder how it has affected your life and future plans?
19. Is there anything else you would like to share with me?

Appendix 2. Interview guide for adolescents with cancer (Armenian version)

**Դեռահասների հետ անհատական գրույցի ուղեցույց  
(հայերեն տարբերակ)**

ID \_\_\_\_\_ Վայր \_\_\_\_\_ Հարցազրույցի սկիզբ \_\_\_\_\_  
Հարցազրույցի ավարտ \_\_\_\_\_

Հարցազրույցավար \_\_\_\_\_ « » \_\_\_\_\_ 2015թ.

Համաձայնության ձևի ներկայացում:

Ներածություն: *Ինչպես արդեն նշեցի, ես ուզում եմ ավելի լավ հասկանալ, թե ինչ կարիքներ ունեն երեխաները/դեռահասները, ովքեր բուժում են ստանում այս հիվանդանոցում, ինչպես նաև իմանալ նրանց ծնողների կարիքների մասին: Ես քեզ խնդրում եմ պատմել ինձ քո փորձի մասին, որը կօգնի մեզ բարելավել/լավացնել/ այն բուժումը, որը դու ստանում ես:*

Պատմիր ինձ քո մասին: *Ինչպե՞ս ես քեզ զգում այսօր: Քանի՞ տարեկան ես: Որտեղի՞ց ես: Ընտանիքիդ ո՞ր անդամի հետ ես մնում հիվանդանոցում:*

**Ֆիզիկական ոլորտ: Հիվանդանոցային ծառայություններ, բուժում, ցավի և կողմնակի ազդեցություններ կառավարում**

**Հիվանդանոցային ծառայություններ/բաժանմունքի պայմաններ**

1. Դու հիվանդանոցում մնո՞ւմ ես բուժման ամբողջ կուրսի ընթացքում (*Փորձ Ամեն օր բուժում ստանալուց հետո դու տուն ես գնո՞ւմ, իսկ հաջորդ օրը նորից վերադառնում*):
2. Քեզ դո՞ւր է գալիս քո հիվանդասենյակը /պալատը/: Քո սենյակում /պալատում/ տա՞ ք է: (Եթե ոչ, ապա ինչ էք միացնում, որ սենյակը տաքացնեք): Դու քո սենյակում մենակ ես մնում, թե այլ հիվանդներ էլ կան քեզ հետ: Ի՞նչ կա քո սենյակում:
  - Հեռուստացույց
  - Սառնարան
  - Հարմարավետ անկողին
  - Առանձին անկողին խնամողի համար /մամայի, տատիկի համար/
  - Առանձին զուգարան
  - Առանձին լոգարան
3. Երբ հիվանդանոցում ես, դու ուտո՞ւմ ես այն ուտելիքները որոնք սիրում ես: (*Փորձ. Ո՞րն է քո սիրելի ուտելիքը/ճաշատեսակը*): Բաժանմունքում խոհանոց ունե՞ք? Քո խնամողը /մայրիկը/ պատրաստ՞ւմ է այդ խոհանոցում:

*Հիմա ես կուզենայի իմանալ, թե դու ինչպե՞ս ես անցկացնում քո ազատ ժամանակը:*

4. Ինչո՞վ ես զբաղվում հիվանդանոցում, երբ ազատ ժամանակ ես ունենում: Դիտո՞ւմ ես հեռուստացույց: (Փորձ. *Հեռուստացույց դիտելն անվճար է, թե պետք է գումար զցես, որ այն միանա: Քանի հեռուստաալիք է ցույց տալիս: Դու ունես սիրելի հաղորդումներ, որոնք նայում ես հիվանդանոցում):* Բաժանմունքում խաղասենյակ ունե՞ք: (Փորձ. *Միտո՞ւմ ես այնտեղ խաղալ/ժամանակ անցկացնել: Խաղասենյակում ի՞նչն ես ամենաշատը սիրում: Կա մի բան, որ կցանկանայիր, որ լիներ խաղասենյակում):* Ունե՞ք խաղահրապարակ հիվանդանոցի բակում: Ո՞րն է սիրած զբաղմունք /հոբի/ ունես: *Եթե այո*- Հիվանդանոցում լինելու ժամանակ դու շարունակո՞ւմ ես քո սիրած զբաղմունքը:

### **Բժիշկների/բուժքույրերի հետ շփումը/նրանց վերաբերմունքը**

5. Ինչպե՞ս են բժիշկները/բուժքույրերը բուժում քեզ: (Փորձ. *Ի՞նչ ես մտածում, բժիշկները հասկանում են, թե քեզ հետ ինչ է կատարվում: Նրանք բարեհամբույր են քեզ հետ: Միտո՞ւմ ես խոսել նրանց հետ):*
6. Որքա՞ն հաճախ են բժիշկները/բուժքույրերը քեզ այցելում և ի՞նչ համար: (Փորձ. *Այցելում են պարզապես զրուցելու, քո ջերմությունը չափելու կամ այլ գործողություն կատարելու համար):*

### **Բուժում, ցավի և կողմնակի ազդեցությունների կառավարում**

7. Ի՞նչ հիվանդություն դու ունես: (Փորձ. *Ո՞րտեղդ է ցավում):*
8. Կարող ես ասել, թե ինչ բուժում/ դեղեր ես ներկայումս ստանում: Դու գո՞հ ես բուժումից, որը ստանում ես: (Փորձ. *Քո բուժման հետ կապված վախ կամ զայրույթ զգո՞ւմ ես: Եթե այո*-կարո՞ղ ես ինձ պատմել այդ մասին):
9. Կարո՞ղ ես պատմել, թե ինչ կողմնակի նշաններ ունես բուժման և դեղորայքի պատճառով: Ինչպե՞ս են կողմնակի ազդեցությունները կառավարվում: (Փորձ. *Ի՞նչ են անում բժիշկները/բուժքույրերը, որպեսզի դու չունենաս կողմնակի նշաններ):* Ինչպե՞ս են կողմնակի նշանները ազդել քո և ընտանիքիդ անդամների կյանքի վրա:
10. Դու ցավ զգո՞ւմ ես: Ի՞նչ աստիճանի ցավ ես դու զգում \_\_\_\_\_ («Ցավը գնահատելու թվային սանդղակ» Հավելված 4): Ի՞նչ են անում բժիշկները/բուժքույրերը, որպեսզի դու ցավեր չունենաս: Դու գո՞հ ես ցավազրկումից, որ ստանում ես:

### **Մոցիալ-հոգեբանական և հոգևոր ոլորտ**

#### **Ընտանիքի անդամներ/բարեկամներ**

11. Պատմիր խնդրում եմ այն օգնության մասին, որը ստանում ես քո ընտանիքի անդամներից: (Փորձ. *Դու խոսո՞ւմ ես նրանց հետ քո ապրումների մասին: Նրանք*

օգն՝ում են քեզ հաղթահարել այս ապրումները: Նրանք մխիթարող/սփոփող՝ում են քեզ, երբ դու տխրում ես հիվանդության պատճառով):

12. Ի՞նչ օգնություն կցանկանայիր ստանալ նրանցից: (Փորձ. Ի՞նչ կուզենայիր, որ նրանք անեին քեզ համար):

### **Ընկերներ**

13. Պատմիր խնդրում եմ այն օգնության մասին, որը դու ստանում ես քո ընկերներից: (Փորձ. Քանի՞ մտերիմ ընկեր դու ունես: Որքա՞ն հաճախ են քո ընկերներն այցելում քեզ):
14. Ի՞նչ օգնություն կցանկանայիր ստանալ քո ընկերներից: (Փորձ. Ի՞նչ կուզենայիր, որ նրանք անեին քեզ համար):

### **Դպրոց**

15. Դու դպրոց հաճախող՝ում ես: Եթե ոչ-դպրոց չհաճախելը ինչպե՞ս է ազդում քեզ վրա: Կցանկանայի՞ր շարունակել քո ուսումը հիվանդանոցում/տանը: Եթե այո-Ինչպե՞ս կուզեիր, որ դա կազմակերպվեր/իրականացվեր:

### **Այլ օգնություն**

16. Ի՞նչ օգնություն ես ներկայումս դու ստանում: (Փորձ. Բաժանմունքում կամ հիվանդանոցում գործող՝ում է հոգեբանական ծառայություն, ուսուցչուհի և այլն): Եթե այո-Դու գո՞հ ես այդ ծառայություններից: Եթե ոչ-Ինչպե՞ս կարող են այս մարդիկ/ծառայությունները քեզ օգտակար լինեն: (Փորձ. Ինչ օգնություն դու կցանկանայիր ստանալ հոգեբանական ծառայությունից, սոցիալական աջխատողի ծառայությունից):

### **Հոգևոր ոլորտ**

17. Ի՞նչն է քեզ ուրախացնում: Քո հիվանդության հետ կապված դու ունե՞ս ինչ-որ վախեր: Ի՞նչն է քեզ ամենաշատը անհանգստացնում/մտահոգում: (Փորձ. Ի՞նչն է քեզ ամենաշատը մտահոգում այն պահից սկսած, երբ հիվանդացար):
18. Մարդիկ հիվանդ լինելուն տարբեր կերպ են արձագանքում: Ես ուզում էի իմանալ, թե հիվանդ լինելը ինչպե՞ս է ազդել քո կյանքի և ապագայի քո ծրագրերի վրա:
19. Կա՞ որևէ այլ բան, որ կցանկանայիր ինձ ասել:

Շնորհակալություն հարցմանը մասնակցելու համար

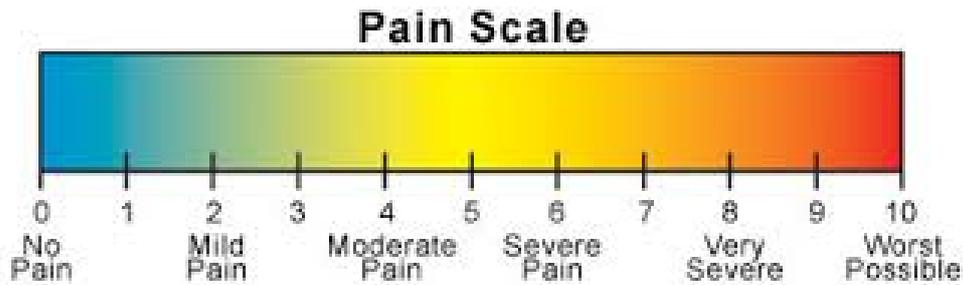
Appendix 3. “0–10 Numeric Pain Rating Scale” (English and Armenian versions)

I would like you to rate your pain on a scale from zero to ten.

2. ‘Zero’ means you have no pain at all.

3. ‘Ten’ means the worst possible pain you can image.

What number would you give to your pain?



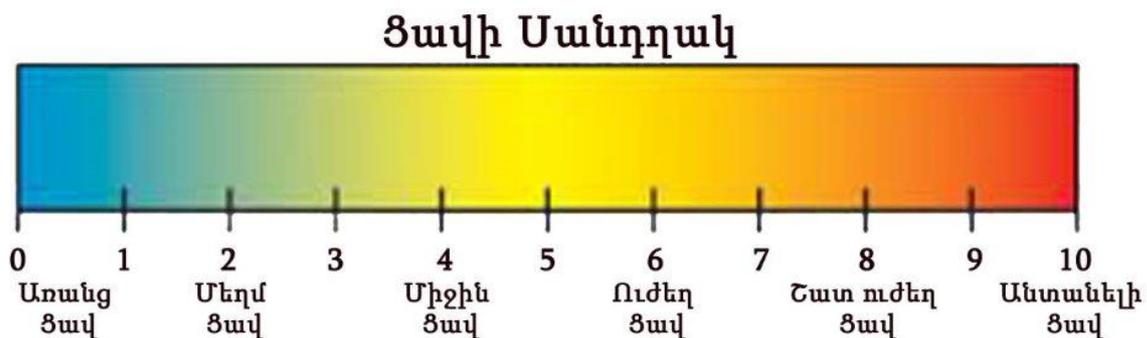
**«Ցավը գնահատելու թվային սանդղակ»**

Բացատրություն: *Խնդրում եմ ընտրիք այն թիվը, որն առավել լավ է նկարագրում այն ցավը, որը դու սովորաբար ունենում ես:*

«0» նշանակում է, որ դու ընդհանրապես ցավ չունես

«10» նշանակում է ամենաուժեղ ցավը, որը դու երբևէ ունեցել ես:

Ի՞նչ թիվ կտաս այն ցավի, որ սովորաբար ունենում ես:



Appendix 4. Interview guide for parents of adolescents with cancer (English version)

ID:

Date:

Place:

Time:

Interviewer:

Provide consent form.

Introduction of the topic: *As I mentioned in the consent form, the aim of this study is to assess pediatric palliative needs of adolescents living with cancer and their family members. Being a parent of a child living with cancer means that you are familiar with this issue, and could provide some important information. So I would kindly ask you to answer several questions to help us to learn more about what it is like to be a parent of a child with cancer in Armenia. Your answers will help us to provide recommendations to improve the care for children living with cancer in the country.*

*I'd like to start by asking you a few questions about yourself.*

1.	Are you citizen of Armenia?	1. Yes 2. No (if not what country) _____
2.	Where do you live?	1. Yerevan 2. Marz (please, specify) _____
3.	What is your family relation with the child who has cancer?	
4.	Date of birth	____/____/____
5.	What is your marital status?	1. Married 2. Separated/Divorced 3. Widowed 4. Single
6.	Indicate the highest level of education that you have received.	1. No education 2. School (10 years or less) 3. Professional technical education (10-13 years) 4. Institute/University or higher
7.	Are you employed?	1. Yes 2. Yes, but on maternity/pregnancy leave 3. No 4. Self-employed 5. Seasonal worker or farmer 6. Student 7. Retired 8. Other (specify) _____
8.	How many adults (aged 18 and over) live in your household	

	(including the respondent)?	
9.	How many children (under 18 years old) live in your household?	
10.	Is your family registered in a family poverty benefit program (e.g. PAROS)?	1. Yes 2. No
11.	On average, how much money does your family spend monthly?	1. Less than 50,000 AMD 2. From 51,000 to 100,000 AMD 3. From 101,000 to 200,000 AMD 4. From 201,000 to 300,000 AMD 5. Above 301,000 AMD 6. 88. Don't know/ I refuse to respond

*I am very interested in hearing your opinion about care and services that you and your child receive in hospital.*

**Physical Domain: Hospital services, treatment, control of pain and side-effects.**

*Hospital services/Ward conditions*

1. Do you and your child stay at the hospital for the whole course of treatment? (*Probe: Every day after receiving your child's treatment do you leave the hospital and come back for the next day?*)
2. How do you like your child's patient room? Is it warm enough? (If no-What do you use to make it warmer?) Do you and your child stay in room alone or share it with other patients? What do you have in your child's patient room?
  - TV
  - Refrigerator
  - Comfortable bed
  - Separate bed for supporter (parent/caregiver)
  - Separate toilet
  - Separate bathroom
3. Do you and your child eat the foods that you like while in the hospital? Do you have a kitchen in the ward? Do you cook there? Do you receive any meal from the hospital?
4. To what extend are you satisfied with the cleanliness in the ward (patient room, playroom, kitchen, toilet facilities, etc.).
5. Approximately, how long do your child and you wait in queue in the health care facility for each treatment? What would you suggest to improve those processes?
6. Approximately how long does it take you to get to the health care facility for receiving the treatment for your child?
7. How often have you visited the health facility with your child for receiving a treatment?
8. What are the main problems you face in the hospital? What are your suggestions to improve the care?

### ***Communication with nurses/doctors/ the attitude of providers***

9. To whom on the health care team do you talk to most about your child? (*Probe: Whom on the health care team do you feel most connected with?*)
10. How do you communicate with healthcare providers? (*Probe: Do you feel you are getting attention and individual approach from healthcare providers?*) Are you satisfied with your communication? Are healthcare providers open to you in terms of discussing the diagnosis/disease? (*Probe: Do you get explanations about why certain procedures are done with your child? Do you get advice on nutrition, on pain management, on other aspects of care? Do physicians consult with you before making decisions about the treatment?*). If the child feels bad, who do you call for help? (*Probe: Do you perform certain procedures yourself, and if so, who taught them? Do you know how to administer pain medication, how often?*).

### ***Treatment, control of pain and side-effects***

*I will ask you some questions about your child's symptoms and how successfully these symptoms have been managed.*

11. What can you say regarding how your child feels after taking the drugs? (*Probe: What side effects does he/she suffer from the drugs?*).
12. How do you/other family members help you to manage the side effects of the drugs?
13. How much pain does your child experience? How do you help your child to manage the pain? Does your child receive medical treatment for pain? How satisfied are you with the pain management?
14. In your opinion, does your child get the best available treatment? Why or why not? What would be the best treatment? What is missing from his treatment now?
15. What do you understand by the term 'palliative care'?

### ***Financial aspects of treatment/care***

16. What can you say about financial issues of the treatment? (*Probe: For what services have you paid for?*). How much money has your family spent on the treatment overall? To what extent your family can afford the treatment expenses? What can you say about the drug availability in the hospital? What happens when drugs are not available?

### ***Psychosocial and Spiritual Domains***

#### ***Family members/relatives and interaction with sick child***

17. Who helps you to care for the child in your family? What kind of help they are providing you? What kind of help would you like to receive?
18. What kind of problems do you face in relationship with your sick child? (*Probe: Does your child aware of his/her diagnosis? If yes-How is he/she reacting to the diagnosis? If no-How do you explain the child his/her condition, why you are at hospital?*).

***Support from others***

19. What kind of help/support do you and your child currently receive? (*Probe: Do you have psychological service, teacher in the ward, etc.?*). If yes-Do you feel you receive the help that you need?). If no -What kind of help would you like to receive from psychological services, from social workers?)
20. What types of governmental support or other type of support does your family receive?

***Spiritual aspect***

21. How did the diagnosis and treatment affect your life and the life of your child?
22. What would you hope could be done for families faced with this situation?
23. Is there anything else you would like to share with me?

Appendix 5. Interview guide for parents of adolescents with cancer (Armenian version)

**Ծնողների հետ անհատական զրույցի ուղեցույց  
(հայերեն տարբերակ)**

ID \_\_\_\_\_ Վայր \_\_\_\_\_ Հարցազրույցի սկիզբ \_\_\_\_\_  
 Հարցազրույցի ավարտ \_\_\_\_\_  
 Հարցազրույցավար \_\_\_\_\_ « » \_\_\_\_\_ 2015թ.

Համաձայնության ձևի ներկայացում:

Ներածություն: *Ինչպես ես նշեցի համաձայնության ձևի մեջ, այս հետազոտության նպատակն է գնահատել քաղցկեղով հիվանդ երեխաների, ինչպես նաև նրանց ընտանիքի անդամների կարիքները: Լինելով քաղցկեղով հիվանդ երեխայի ծնող, Դուք ծանոթ եք այս խնդրին և կարող եք կարևոր տեղեկություններ հայտնել: Հետևաբար Ձեզ խնդրում եմ պատասխանել իմ հարցերին, որոնք հնարավորություն կտան հասկանալու, թե ինչ է նշանակում լինել հիվանդ երեխայի ծնող Հայաստանում: Ձեր պատասխանները մեզ հնարավորություն կտան մշակելու քայլեր, որոնք հետագայում կբարելավեն երեխաների խնամքը:*  
*Մեր զրույցը սկսելու առաջ, կուզենայի մի քանի հարց տալ Ձեր մասին:*

1.	Դուք Հայաստանի՞ քաղաքացի եք:	1. Այո 2. Ոչ (նշեք) _____
2.	Որտե՞ղ եք Դուք բնակվում:	1. Երևան 2. Մարզ (նշեք) _____
3.	Ձեր ազգակցական կապը քաղցկեղով հիվանդ երեխայի հետ (այսինքն Դուք իրա ի՞նչն եք)	
4.	Ծննդյան տարեթիվ:	____/____/____
5.	Ձեր ամուսնական կարգավիճակը:	1. Ամուսնացած 2. Բաժանված 3. Ամուսինը/կինը մահացած 4. Չամուսնացած
6.	Ձեր ամենաբարձր կրթական աստիճանը:	1. Կրթություն չունեմ 2. Միջնակարգ (10 տարի կամ քիչ) 3. Միջին մասնագիտական (10-13 տարի) 4. Բարձրագույն (ինստիտուտ/համալսարան) և ավել

7.	Դուք ներկայումս աշխատում ե՞ք:	1. Այո 2. Այո/Ֆիզարձակուրդ 3. Ոչ 4. Ինքնազբաղված եմ /սեփական գործ/ 5. Մեզոնային աշխատող 6. Ուսանող 7. Թոշակառու 8. Այլ (նշեք) _____
8.	Քանի՞ չափահաս է ապրում Ձեր ընտանիքում (Դուք էլ միասին):	
9.	Քանի՞ անչափահաս է բնակվում Ձեր տանը:	
10.	Ձեր ընտանիքը գրանցված է ՓԱԲՈՍ-ի ծրագրում:	1. Այո 2. Ոչ
11.	Միջինում, ամսական ամեն ինչի վրա որքա՞ն գումար է ծախսում Ձեր ընտանիքը:	1. 50 000 դրամից քիչ 2. 51 000 – 100 000 դրամ 3. 101 000 – 200 000 դրամ 4. 201 000 – 300 000 դրամ 5. 301 000 դրամից ավել 88.Չգիտեմ/հրաժարվում եմ պատասխանել

*Հետևյալ հարցերը վերաբերում են խնամքին և ծառայություններին, որոնք Դուք և Ձեր երեխան ստանում ենք հիվանդանոցում:*

**Ֆիզիկական ուրրտ: Հիվանդանոցային ծառայություններ, բուժում, ցավի և կողմնակի ազդեցություններ կառավարում**

***Հիվանդանոցային ծառայություններ/բաժանմունքի պայմաններ***

- Դուք հիվանդանոցում մնո՞ւմ ես բուժման ամբողջ կուրսի ընթացքում (Փորձ. Ամեն օր բուժում ստանալուց հետո Դուք և Ձեր երեխան տուն եք գնո՞ւմ, իսկ հաջորդ օրը նորից վերադառնո՞ւմ):
- Ձեզ դո՞ւր է գալիս ձեր երեխայի հիվանդասենյակը /պալատը/: Սենյակում /պալատում/ տա՞ք է: (Եթե ոչ, ապա ինչ եք միացնում, որ սենյակը տաքացնեք): Դուք սենյակում մենակ ես մնում, թե այլ հիվանդներ էլ կան ձեզ հետ: Ի՞նչ կա ձեր երեխայի հիվանդասենյակում /պալատում/:
  - Հեռուստացույց
  - Սառնարան
  - Հարմարավետ անկողին
  - Առանձին անկողին խնամողի համար /մամայի, տատիկի համար/

- Առանձին զուգարան
  - Առանձին լոգարան
3. Հիվանդանոցում մնալու ընթացքում, Դուք և Ձեր երեխան ուտո՞ւմ եք այն ուտելիքները որոնք սիրում եք: Բաժանմունքում խոհանոց ունե՞ք? Եթե այո-Դուք այնտեղ պատրաստո՞ւմ եք: Որևէ սնունդ ստանո՞ւմ եք հիվանդանոցից:
  4. Դուք բավարարվա՞՞ծ եք/զո՞հ եք բաժանմունքում տիրող մաքրությունից (հիվանդասենյակների, խաղասենյակի, խոհանոցի, զուգարանների և այլն):
  5. Ինչքա՞ն երկար եք Դուք և Ձեր երեխան ստիպված լինում հերթի մեջ մնալ հիվանդանոցում յուրաքանչյուր բուժման համար: Ի՞նչ կառաջարկեիք այդ գործընթացը բարելավելու համար:
  6. Ինչքա՞ն ժամանակ է Ձեզանից պահանջվում/խլում երեխայի բուժումը ստանալու համար հիվանդանոց հասնելը:
  7. Որքա՞ն հաճախ եք Դուք այցելում հիվանդանոց երեխայի բուժում ստանալու նպատակով:
  8. Որո՞նք են այն հիմնական խնդիրները, որոնք Դուք հանդիպում եք հիվանդանոցում: Ի՞նչ կառաջարկեիք խնամքը բարելավելու համար:

***Բժիշկների/բուժքույրերի հետ շփումը/նրանց վերաբերմունքը***

9. Բուժանձնակազմից ո՞ւմ հետ եք ամենահաճախը զրուցում երեխայի խնդիրների մասին (Փորձ. *Բուժանձնակազմից ո՞ւմ հետ եք ամենամտերիվը*):
10. Պատմեք խնդրում եմ Ձեր և բուժանձնակազմի հետ ունեցած շփման մասին: (Փորձ. *Դուք զգո՞ւմ եք, որ բուժանձնակազմը Ձեր երեխայի բուժման նկատմամբ անհատական մոտեցում է ցուցաբերում*): Դուք բավարարվա՞՞ծ եք/զո՞հ եք այդ շփումից: Բուժանձնակազմը քննարկո՞ւմ է Ձեզ հետ երեխայի ախտորոշումը: (Փորձ. *Դուք բացատրություններ ստացե՞լ եք բուժանձնակազմից, թե ինչո՞ւ են նրանք իրականացնում այս կամ այն պրոցեդուրաները երեխայի հետ: Ձեզ պատմե՞լ են երեխայի սննդակարգի, ցավի հաղթահարման կամ ընդհանրապես երեխայի խնամքի մասին: Բուժաշխատողները Ձեզ հետ խորհրդակցե՞լ են երեխայի բուժումը սկսելուց առաջ*): Եթե երեխան իրեն վատ է զգում, ո՞ւմ եք Դուք զանգահարում օգնության համար: (Փորձ. *Դուք կարո՞ղ եք ինքներդ մեղմել երեխայի ցավը, եթե այո, ապա ո՞վ է Ձեզ սովորեցրել*):

***Բուժում, ցավի և կողմնակի ազդեցությունների կառավարում***

*Հետևյալ հարցերը վերաբերում են Ձեր երեխայի մոտ առկա ախտանշաններին և դրանց կառավարմանը:*

11. Ի՞նչ կարող եք պատմել այն մասին, թե ինչպես է Ձեր երեխան իրեն զգում դեղեր ընդունելուց հետո: (Փորձ. *Ի՞նչ կողմնակի նշաններ է Ձեր երեխան ունենում դեղերի ընդունումից հետո*):

12. Ինչպե՞ս էք Դուք/ընտանիքի այլ անդամ օգնում երեխային հաղթահարել կողմնակի նշանների ազդեցությունները:
13. Ի՞նչ աստիճանի ցավ է զգում Ձեր երեխան: Ինչպե՞ս էք օգնում Ձեր երեխային հաղթահարել/կառավարել ցավը: Ձեր երեխան դեղորայք ստանո՞ւմ է ցավը հաղթահարելու/մեղմելու համար: Դուք բավարարվա՞՞ծ եք ցավի կառավարումից, որը ստանում է Ձեր երեխան:
14. Ձեր կարծիքով, Ձեր երեխան ստանո՞ւմ է առկա ամենալավ բուժումը: Ինչո՞ւ այո և ինչո՞ւ ոչ: Ո՞րը կլիներ լավագույն բուժումը Ձեր երեխայի համար: Ձեր կարծիքով, ի՞նչն է բացակայում երեխայի բուժման մեջ ներկայումս:
15. Ի՞նչ էք Դուք հասկանում «ամոքիչ»/ «պալիատիվ» բուժում ասելով:

***Բուժման ֆինանսական կողմը***

16. Ի՞նչ կարող էք պատմել բուժման ֆինանսական կողմի մասին: (Փորձ. Ո՞ր ծառայությունների համար էք Դուք վճարում): Որքա՞ն գումար է ընդհանուր առմամբ Ձեր ընտանիքը վճարում երեխայի բուժման համար: Կարողանո՞ւմ է արդյոք Ձեր ընտանիքը վճարել բուժման ծախսերը: Պատմեք խնդրում եմ հիվանդանոցում դեղորայքի առկայության մասին: Ի՞նչ է պատահում, երբ դեղորայք չի լինում հիվանդանոցում:

***Սոցիալ-հոգեբանական և հոգևոր ոլորտ***

***Ընտանիքի անդամներ/բարեկամներ***

17. Ո՞վ է Ձեր ընտանիքում օգնում Ձեզ երեխայի խնամքի հարցում: Ի՞նչ օգնություն/աջակցություն են ընտանիքի անդամները Ձեզ տրամադրում: Ի՞նչ աջակցություն Դուք կցանկանայիք ստանալ ընտանիքի անդամներից:
18. Ի՞նչ խնդիրներ էք Դուք ունենում Ձեր հիվանդ երեխայի հետ շփման ընթացքում: (Փորձ. Ձեր երեխան տեղյա՞կ է իր ախտորոշման (դիագնոզի) մասին: Եթե այո- Ինչպե՞ս նա վերաբերվում (արձագանքում) հիվանդությանը: Եթե ոչ-Ինչպե՞ս էք ասել երեխային, թե ինչու է նա հիվանդանոցում):

***Այլ օգնություն/աջակցություն***

19. Ի՞նչ օգնություն/աջակցություն էք Դուք և Ձեր երեխան ներկայումս ստանում: (Փորձ. Բաժանմունքում աշխատո՞ւմ են հոգեբանները, սոցիալական աշխատողներ, և այլն: Եթե այո, ապա Ձեր կարծիքով Դուք ստանում էք առկա ամենալավ աջակցությունը: Եթե ոչ, ապա ինչ տեսակի աջակցություն Դուք կցանկանայիք ստանալ հոգեբաններից, սոցիալական աշխատողներից և այլն):
20. Ի՞նչ տեսակի աջակցություն/օգնություն էք ստանում կառավարության կողմից:

***Հոգևոր ոլորտ***

21. Ինչպե՞ս է երեխայի ախտորոշումը ազդել Ձեր և Ձեր ընտանիքի անդամների կյանքի վրա:
22. Ձեր կարծիքով, ի՞նչ կարելի է անել այն ընտանիքների համար, ովքեր առընչվել են այս խնդրին:
23. Կա՞ էլի որևէ բան, որ Դուք կցանկանայիք ինձ ասել:

Շնորհակալություն հարցմանը մասնակցելու համար

Appendix 6. Data collected from child's medical record (English and Armenian versions)

1.	What is child gender?	1. Male 2. Female
2.	What is child's date of birth?	____/____/____
3.	When has child first been diagnosed with cancer?	
4.	What is the type of cancer?	
5.	What is the stage of cancer?	
6.	What type of treatment does child receive?	
7.	Has child undergone surgery?	1. Yes (if yes, when and for what reason?) _____ 2. No
8.	Does child have any disability?	1. Yes 2. No 3. Disability due to cancer _____

**Հետևյալ տեղեկությունները պետք է հավաքվեն երեխայի բժշկական քարտից**

1.	Երեխայի սեռը:	1. արական 2. իգական
2.	Երեխայի ծննդյան տարեթիվը:	____/____/____
3.	Ե՞րբ է երեխան առաջին անգամ ախտորոշվել քաղցկեղով:	
4.	Ո՞րն է քաղցկեղի տեսակը:	
5.	Քաղցկեղի զարգացման ո՞ր փուլում է գտնվում երեխան ներկայումս:	
6.	Ի՞նչ բուժում է ստացել երեխան:	
7.	Երեխան վիրահատվե՞լ է, թե ոչ:	1. Այո (երբ և ինչի պատճառով) _____ _____ 2. Ոչ
8.	Երեխան ունի՞ հաշմանդամություն, թե ոչ:	1. Այո 2. Ոչ 3. Հաշմանդամություն քաղցկեղի պատճառով _____

Appendix 7. Consent form for parents (English version)  
American University of Armenia  
Institutional Review Board #1 Consent form

Hello, my name is Armine. I am a psychologist and the graduate student of the Master of Public Health program at the American University of Armenia. Our department is conducting a study to assess needs of adolescents living with cancer and their family members.

You and your child are invited to participate in this study because your child is registered and receiving cancer-directed treatment at one of the Oncology Hospitals in Yerevan. Permission to contact you and your child has been received from the head of department and your child's treating doctor. Your participation will involve face-to-face interview with the duration of up to 1.5 hours. Interview will be conducted in time and place that are convenient for you and your child. Your child's and your participation in this study is voluntary. There is no penalty if you refuse to participate in this study. You can skip any questions you don't want to answer or even stop the interview.

Participation in this study does not have any direct benefit for you, but your participation is valuable for us and will contribute to better understanding of the needs of children living with cancer, as well as the need of their parents. Participation in this study may cause emotional distress to you and your child, thus after interview completion you and your child will be offered psychological consulting. Psychological consulting will be provided by me, as I am a psychotherapist and have 2 year experience of working with children living with cancer.

The information provided by you and your child, as well as data obtained from the medical records are fully confidential and will be used only for the study. Your name will not appear on the questionnaire. Although only the general findings will be presented in the report, some direct quotes from our conversation will be presented in the final report without mentioning your/your child's name.

With your permission, I will use audio-recording to make sure that we will not miss any of the information you provide us with. But you should be aware that it is within your right to ask to turn off the recorder at any time during the interview, whenever you want to.

Before we begin I want to make sure that you have received answers to questions that interest you. Do you have any other questions regarding your participation? If you have any questions regarding this study you can contact the Principal Investigator Dr. Tsovinar Harutyunyan at (060) 61 2560.

If you feel you have not been treated fairly or think you have been hurt by joining the study you should contact Dr. Kristina Akopyan, the Human Subject Protection Administrator of the American University of Armenia (060) 61 25 61.

Do you agree to participate? Please circle  YES  NO

Do you agree to audio-recording? Please circle  YES  NO

If you are ready now we will start.

By signing this document you agree to participate in the study described above.

\_\_\_\_\_  
Name of subject                      Signature                      « » \_\_\_\_\_ 2015  
Date

\_\_\_\_\_  
Name of Person Obtaining Authorization                      Signature                      « » \_\_\_\_\_ 2015  
Date

Appendix 8. Consent form for parents (Armenian version)

Հայաստանի ամերիկյան համալսարան

Հանրային առողջապահության բաժին

Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով

Իրազեկ համաձայնության ձև

Բարև Ձեզ, իմ անունը Արմինե է: Ես հոգեբան եմ և միաժամանակ սովորում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության մագիստրոսական ծրագրի ավարտական կուրսում: Մեր բաժինն իրականացնում է հետազոտություն, որի նպատակն է գնահատել քաղցկեղով հիվանդ դեռահասների և նրանց ընտանիքի անդամների ամոքիչ (պալիատիվ) կարիքները: Դուք և Ձեր երեխան հրավիրված եք մասնակցելու այս հետազոտությանը, քանի որ Ձեր երեխան գրանցված է և բուժում է ստանում Երևանի Ուռուցքաբանական հիվանդանոցներից մեկում: Ձեզ դիմելու թույլտվություն ես ստացել եմ բաժնի վարիչից և Ձեր երեխայի բուժող բժշկից: Ձեր մասնակցությունը սահմանափակվում է միայն մեկ անհատական հարցազրույցով, որը կտևի 1,5 ժամ: Հարցազրույցը կիրականացվի Ձեզ և Ձեր երեխային հարմար ժամին և վայրում, որը կարող ենք նախապես պայմանավորվել: Ձեր և Ձեր երեխայի մասնակցությունն այս հետազոտությունում կամավոր է: Ձեզ ոչինչ չի սպառնում, եթե Դուք հրաժարվեք մասնակցել այս հետազոտությանը: Դուք կարող եք հրաժարվել պատասխանել ցանկացած հարցի կամ ցանկացած պահի ընդհատել հարցազրույցը:

Հետազոտությունում Ձեր և Ձեր երեխայի մասնակցությունը չի նախատեսում որևէ անմիջական օգուտ, սակայն Ձեր անկեղծ պատասխանները չափազանց կարևոր են մեզ համար և կօգնեն ավելի խորը ուսումնասիրել քաղցկեղով հիվանդ երեխաների և նրանց ծնողների կարիքները: Այս հետազոտության ընթացքում Դուք և Ձեր երեխան կարող եք հուզական լարվածություն ունենալ, այդ իսկ պատճառով հարցազրույցի ավարտից հետո ձեզ կառաջարկեմ հոգեբանական խորհրդատվություն: Խորհրդատվությունը կիրականացնեմ ես, քանի որ հոգեբան եմ և քաղցկեղով հիվանդ երեխաների հետ աշխատելու 2 տարվա փորձ ունեմ:

Ձեր և Ձեր երեխայի կողմից տրամադրված ինֆորմացիան, ինչպես նաև բժշկական փաստաթղթերից ստացված տեղեկատվությունը կպահպանվի գաղտնի և կկիրառվի միայն

հետազոտական նպատակներով: Ձեր և Ձեր երեխայի անունը գրված չի լինի

հարցաթերթիկների վրա:

Ձեր համաձայնությամբ ես կձայնագրեմ մեր հարցազրույցը, որպեսզի ոչ մի կարևոր ինֆորմացիա բաց չթողնեմ: Սակայն Դուք պետք է տեղյակ լինեք, որ Ձեր իրավունքն է պահանջել անջատել ձայնագրիչը հետազոտության ընթացքում ցանկացած պահի: Թեև միայն ամփոփված տվյալները կներկայացվեն վերջնական զեկույցում, այնուամենայնիվ մեր զրույցից որոշ մեջբերումներ ներկայացվեն վերջնական զեկույցում՝ առանց նշելու Ձեր կամ Ձեր երեխայի անունը: Մինչ մենք կսկսենք, ես կցանկանայի համոզվել, որ Դուք ստացել եք Ձեզ հուզող հարցերի պատասխանները: Դուք ունեք որևէ այլ հարց կապված այս հետազոտությունում Ձեր մասնակցության վերաբերյալ: Դուք ստացե՞լ եք Ձեզ հուզող հարցերի պատասխանները:

Այս հետազոտության վերաբերյալ հարցեր ունենալու դեպքում կարող եք կապ հաստատել հետազոտության համակարգողի՝ Ծովինար Հարությունյանի հետ հետևյալ հեռախոսահամարով՝ (060) 61 25 60: Եթե կարծում եք, որ Ձեզ հետ ճիշտ չեմ վարվել կամ որևէ կերպ վիրավորել եմ հարցազրույցի մասնակցության ընթացքում, Դուք կարող եք դիմել Հայաստանի ամերիկյան համալսարանի գիտական էթիկայի հանձնաժողովի համակարգող՝ Քրիստինա Հակոբյանին հետևյալ հեռախոսահամարով (060) 61 25 61.

Դուք համաձայն եք մասնակցել: Խնդրում եմ նշել O ԱՅՈ      O ՈՉ

Դուք համաձայն եք, որ ես միացնեմ ձայնագրիչը: Խնդրում եմ նշել O ԱՅՈ      O ՈՉ

Եթե Դուք պատրաստ եք մենք կարող ենք սկսել:

Ստորագրելով այս փաստաթուղթը ես համաձայնվում եմ մասնակցել վերոնշյալ հետազոտությանը:

\_\_\_\_\_ « » \_\_\_\_\_ 2015թ.  
Մասնակցի անուն, ազգանուն      ստորագրություն      ամսաթիվ

\_\_\_\_\_ « » \_\_\_\_\_ 2015թ.  
Համաձայնությունը ստացող անձի անուն, ազգանուն      ստորագրություն      ամսաթիվ

Appendix 9. Consent form for 19 years old Adolescents (English version)  
American University of Armenia  
Institutional Review Board #1

Hello, my name is Armine. I am a psychologist and the graduate student of the Master of Public Health program at the American University of Armenia. Our department is conducting a study to assess the needs of adolescents who are receiving treatment in this hospital, as well as the needs of their parents.

You are invited to participate in this study because you are registered and receiving treatment in this Hospital. Permission to contact you has been received from the head of department and your treating doctor. Your participation will involve face-to-face interview with the duration of up to 1.5 hours. Interview will be conducted in time and place that are convenient for you. Your participation in this study is voluntary. There is no penalty if you refuse to participate in this study. You can skip any questions you don't want to answer or even stop the interview.

Participation in this study does not have any direct benefit for you, but your participation is valuable for us and will contribute to better understanding of the needs of adolescents who are receiving treatment in this hospital, as well as the need of their parents. Participation in this study may cause emotional distress to you, thus after interview completion you will be offered psychological consulting. Psychological consulting will be provided by me, as I am a psychotherapist.

The information provided by you, as well as data obtained from the medical records are fully confidential and will be used only for the study. Your name will not appear on the questionnaire. Although only the general findings will be presented in the report, some direct quotes from our conversation will be presented in the final report without mentioning your name.

With your permission, I will use audio-recording to make sure that we will not miss any of the information you provide us with. But you should be aware that it is within your right to ask to turn off the recorder at any time during the interview, whenever you want to.

Before we begin I want to make sure that you have received answers to questions that interest you. Do you have any other questions regarding your participation? If you have any questions regarding this study you can contact the Principal Investigator Dr. Tsovinar Harutyunyan at (060) 61 25 60.

If you feel you have not been treated fairly or think you have been hurt by joining the study you should contact Dr. Kristina Akopyan, the Human Subject Protection Administrator of the American University of Armenia (060) 61 25 61.

Do you agree to participate? Please circle  YES  NO

Do you agree to audio-recording? Please circle

YES

NO

If you are ready now we will start.

By signing this document you agree to participate in the study described above.

\_\_\_\_\_  
Name of subject

\_\_\_\_\_  
Signature

« » \_\_\_\_\_ 2015  
Date

\_\_\_\_\_  
Name of Person Obtaining Authorization

\_\_\_\_\_  
Signature

« » \_\_\_\_\_ 2015  
Date

Appendix 10. Consent form for 19 years old Adolescents (Armenian version)

Հայաստանի ամերիկյան համալսարան  
Հանրային առողջապահության բաժին  
Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով  
Իրազեկ համաձայնության ձև

Բարև, իմ անունը Արմինե է: Ես հոգեբան եմ և միաժամանակ սովորում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության մագիստրոսական ծրագրի ավարտական կուրսում: Մեր բաժինն իրականացնում է հետազոտություն, որի նպատակն է գնահատել, թե ինչ կարիքներ ունեն երեխաները/դեռահասները, ովքեր բուժում են ստանում այս հիվանդանոցում, ինչպես նաև իմանալ նրանց ծնողների կարիքները: Դուք հրավիրված եք մասնակցելու այս հետազոտությանը, քանի որ գրանցված եք և բուժում եք ստանում այս հիվանդանոցում: Ձեզ դիմելու թույլտվություն ես ստացել եմ բաժնի վարիչից և ձեր բուժող բժշկից: Ձեր մասնակցությունը սահմանափակվում է միայն մեկ անհատական հարցազրույցով, որը կտևի 1,5 ժամ: Հարցազրույցը կիրականացվի Ձեզ հարմար ժամին և վայրում, որը կարող ենք նախապես պայմանավորվել: : Ձեր մասնակցությունն այս հետազոտությունում կամավոր է: Ձեզ ոչինչ չի սպառնում, եթե Դուք հրաժարվեք մասնակցել այս հետազոտությանը: Դուք կարող եք հրաժարվել պատասխանել ցանկացած հարցի կամ ցանկացած պահի ընդհատել հարցազրույցը:

Հետազոտությունում Ձեր մասնակցությունը չի նախատեսում որևէ անմիջական օգուտ, սակայն Ձեր անկեղծ պատասխանները չափազանց կարևոր են մեզ համար և կօգնեն ավելի խորը ուսումնասիրել երեխաների/դեռահասների կարիքները, ովքեր բուժում են ստանում այս հիվանդանոցում: Այս հետազոտության ընթացքում Դուք կարող եք հուզական լարվածություն ունենալ, այդ իսկ պատճառով հարցազրույցի ավարտից հետո ձեզ կառաջարկեն հոգեբանական խորհրդատվություն: Խորհրդատվությունը կիրականացնեն ես, քանի որ հոգեբան եմ:

Ձեր կողմից տրամադրված ինֆորմացիան, ինչպես նաև բժշկական փաստաթղթերից ստացված տեղեկատվությունը կպահպանվի գաղտնի և կկիրառվի միայն հետազոտական նպատակներով: Ձեր անունը գրված չի լինի հարցաթերթիկների վրա: Թեև միայն ամփոփված

տվյալները կներկայացվեն վերջնական գեկույցում, այնուամենայնիվ մեր գրույցից որոշ մեջբերումներ ներկայացվեն վերջնական գեկույցում՝ առանց նշելու Ձեր անունը:

Ձեր համաձայնությամբ ես կձայնագրեմ մեր հարցազրույցը, որպեսզի ոչ մի կարևոր ինֆորմացիա բաց չթողնեմ: Սակայն Դուք պետք է տեղյակ լինեք, որ Ձեր իրավունքն է պահանջել անջատել ձայնագրիչը հետազոտության ընթացքում ցանկացած պահի: Եթե ՈՁ, ապա ես գրառումներ կիրականացնեմ հարցազրույցի ընթացքում:

Մինչ մենք կսկսենք, ես կցանկանայի համոզվել, որ Դուք ստացել եք Ձեզ հուզող հարցերի պատասխանները: Դուք ունեք որևէ այլ հարց կապված այս հետազոտությունում Ձեր մասնակցության վերաբերյալ: Դուք ստացե՞լ եք Ձեզ հուզող հարցերի պատասխանները:

Այս հետազոտության վերաբերյալ հարցեր ունենալու դեպքում կարող եք կապ հաստատել հետազոտության համակարգողի՝ Ծովինար Հարությունյանի հետ հետևյալ հեռախոսահամարով՝ (060) 61 25 60: Եթե կարծում եք, որ Ձեզ հետ ճիշտ չեմ վարվել կամ որևէ կերպ վիրավորել եմ հարցազրույցի մասնակցության ընթացքում, Դուք կարող եք դիմել Հայաստանի ամերիկյան համալսարանի գիտական էթիկայի հանձնաժողովի համակարգող՝ Քրիստինա Հակոբյանին հետևյալ հեռախոսահամարով (060) 61 25 61.

Դուք համաձայն եք մասնակցել: Խնդրում եմ նշել O ԱՅՈ O ՈՁ

Դուք համաձայն եք, որ ես միացնեմ ձայնագրիչը: Խնդրում եմ նշել O ԱՅՈ O ՈՁ

Եթե Դուք պատրաստ եք մենք կարող ենք սկսել:

Ստորագրելով այս փաստաթուղթը ես համաձայնվում եմ մասնակցել վերոնշյալ հետազոտությանը:

\_\_\_\_\_  
Մասնակցի անուն, ազգանուն \_\_\_\_\_ ստորագրություն « » \_\_\_\_\_ 2015թ.  
ամսաթիվ

\_\_\_\_\_  
Համաձայնությունը ստացող անձի անուն, ազգանուն \_\_\_\_\_ ստորագրություն « » \_\_\_\_\_ 2015թ.  
ամսաթիվ

Appendix 11. Assent form for Children Ages 10-18 (English version)

American University of Armenia  
Institutional Review Board #1

Hi. My name is Armine. I am a psychologist and the graduate student of the School of Public Health at the American University of Armenia. Right now, I am learning about the needs of children/adolescents who are receiving treatment in this hospital, as well as the needs of their parents. I would like to ask you to talk to me and answer to my questions, but before I want to explain what will happen if you decide to talk to me.

I will ask you questions about your treatment, as well as about your difficulties while being sick, about your feelings, mood and wishes. There is no right or wrong answers; I just want to know your opinion. If you allow me I will record our conversation in order not to miss any information. If no, I will just take notes while you are speaking. Participation in this conversation does not have any direct benefit for you, but your participation is very valuable for us.

If during our conversation you feel upset or sad, you and I can discuss it. After completion of these questions if you want we can also discuss anything that bothers you. Your (parents and) treating doctors will not know what you have said to me. When I tell other people about our conversation, I will not use your name, and no one will be able to know who I'm talking about.

Your mom/dad says it is okay for you to talk to me and answer to my questions. But if you do not want, you do not have to talk. I won't be upset, and no one else will be upset, if you don't want to talk. If you want to talk to me and answer to my questions now but change your mind later, that's okay. You can stop at any time.

You can ask me questions about conversation. If there is anything you don't understand you should tell me and I can explain it to you.

Do you have any questions for me now?

Would you like to talk to me and answer some questions?

"This project has been explained to my child in my presence, in language he/she can understand. He/she has been encouraged to ask questions both now, and in the future, about the research study."

By signing this document I allow my child to participate in the study described above.

\_\_\_\_\_ « » \_\_\_\_\_ 2015  
Name of parent                      Signature                      Date

By signing this document I agree to participate in the study described above.

\_\_\_\_\_ « » \_\_\_\_\_ 2015  
Name of child                      Signature                      Date

\_\_\_\_\_ « » \_\_\_\_\_ 2015  
Name of Person Obtaining Authorization                      Signature                      Date

Appendix 12. Assent form for Children Ages 10-18 (Armenian version)

Հայաստանի ամերիկյան համալսարան  
Հանրային առողջապահության բաժին  
Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով  
Իրազեկ համաձայնության ձև

Բարև, իմ անունը Արմինե է: Ես հոգեբան եմ և միաժամանակ սովորում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության բաժնում: Ես ուզում եմ ծանոթանալ, թե ինչ կարիքներ ունեն երեխաները/դեռահասները, ովքեր բուժում են ստանում այս հիվանդանոցում, ինչպես նաև իմանալ նրանց ծնողների կարիքները: Դու ինձ շատ օգնած կլինես, եթե ցանկանաս գրուցել ինձ հետ և պատասխանել իմ հարցերին: Մակայն մինչ դա ես պետք է ներկայացնեմ քեզ, թե ինչի մասին է լինելու գրույցը: Զրույցի ընթացքում ես քեզ հարցնելու եմ քո բուժման, քո տրամադրության, զգացմունքների, ցանկությունների մասին, ինչպես նաև այն բոլոր խնդիրների, որոնք առաջացել են քեզ մոտ հիվանդության պատճառով: Չկան ճիշտ կամ սխալ պատասխաններ, ես պարզապես ուզում եմ իմանալ քո կարծիքը: Եթե դու թույլ տաս, ես կձայնագրեմ մեր գրույցը, որպեսզի ոչ մի կարևոր բան բաց չթողնեմ քո ասածներից: Իսկ եթե դու չես ցանկանա, ապա ես միայն գրառումներ կանեմ մեր գրույցի ընթացքում: Այս գրույցին մասնակցելը քեզ ոչ մի ուղղակի օգուտ չի տա, սակայն քո պատասխանները չափազանց կարևոր են մեզ համար:

Եթե գրույցի ընթացքում դու տխրես կամ քեզ վատ զգաս, մենք դրա մասին անպայման կխոսենք: Երբ բոլոր հարցերին պատասխանես, մենք կարող ենք խոսել ցանկացած այլ բանի մասին, ինչը քեզ անհանգստացնում է: Քո (ծնողները) և բուժող բժիշկը չեն իմանա, թե մենք ինչի մասին ենք գրուցել: Երբ ես այլ մարդկանց պատմեմ այս գրույցի մասին, ես չեմ նշելու քո անունը, և ոչ ոք չի իմանա, թե ով է խոսողը:

Քո ծնողները թույլ են տվել, որ դու մասնակցես այս գրույցին: Մակայն, եթե դու չես ցանկանում մասնակցել, ապա կարող ես հրաժարվել: Ես չեմ նեղանա, ու ոչ ոք չի նեղանա քեզանից, եթե դու հրաժարվես մասնակցել: Կամ եթե դու հիմա համաձայնվես մասնակցել, բայց հետո փոխես քո միտքը, մենք չենք շարունակի մեր գրույցը: Դու կարող ես ինձ հարցեր տալ ապագա գրույցի վերաբերյալ: Եթե կա մի բան, որ դու չհասկացար, դու կարող ես հարցնել, և ես կպատասխանեմ: Դու հիմա հարցեր ունե՞ս: Կցանկանա՞ս մասնակցել գրույցին ու պատասխանել իմ հարցերին:

«Այս հետազոտության նպատակը բացարվել է իմ երեխային իմ ներկայությամբ, երեխային հասկանալի լեզվով: Երեխան տեղեկացված է, որ հետազոտության վերաբերյալ կարող է հարցեր տալ ինչպես հիմա, այնպես էլ հետագայում»:

Ստորագրելով այս փաստաթուղթը ես թույլ եմ տալիս իմ երեխային մասնակցել վերոնշյալ հետազոտությանը:

\_\_\_\_\_ « » \_\_\_\_\_ 2015թ.  
Ծնողի անուն, ազգանուն ստորագրություն ամսաթիվ

Ստորագրելով այս փաստաթուղթը ես համաձայնվում եմ մասնակցել վերոնշյալ հետազոտությանը:

\_\_\_\_\_ « » \_\_\_\_\_ 2015թ.  
Երեխայի անուն, ազգանուն ստորագրություն ամսաթիվ

\_\_\_\_\_ « » \_\_\_\_\_ 2015թ.  
Համաձայնությունը ստացող անձի անուն, ազգանուն ստորագրություն ամսաթիվ

## Appendix 13. IRB approval letter



American  
University  
of Armenia | Հայաստանի  
Ամերիկյան  
Համալսարան

February 05, 2015

Hripsime Martirosyan MD, MPH  
40 Marshal Baghramian  
Yerevan 0019, Armenia

PRINCIPAL INVESTIGATOR: Tsovinar Harutyunyan, MPH, PhD  
Co-INVESTIGATOR: Sarah Kagan, PhD, RN  
STUDENT INVESTIGATOR: Armine Abrahamyan  
TITLE: Pediatric Palliative Care in Armenia: a qualitative analysis of the needs of adolescents with cancer and their parents  
SPONSORING AGENCY: None  
PROTOCOL #: AUA-2015-006

Tsovinar Harutyunyan, MPH, PhD, Armine Abrahamyan  
Via Email: [tsovinar@aua.am](mailto:tsovinar@aua.am); [armine\\_abrahamyan@edu.aua.am](mailto:armine_abrahamyan@edu.aua.am)

Dear Dr. Harutyunyan and Ms. Abrahamyan,

The above referenced protocol was reviewed and approved by the Chair of the Institutional Review Board for Clinical Studies of the American University of Armenia using the full board review set forth in 45 CFR 46.406 on February 05, 2015. This study will be due for continuing review on or before February 05, 2016. Annual continuing reviews will be required for this proposal. The proposed study can proceed as it is approved by the AUA IRB. However, please note, the IRB must be kept apprised of any and all changes in the research that may have an impact on the level and type of IRB review needed for a specific proposal. You are required to notify the AUA IRB if any changes are proposed in the study that might alter its IRB status and consent procedures. New procedures that may have an impact on the risk-to-benefit ratio cannot be initiated until IRB approval has been given. Please retain this letter as documentation of the IRB's determination regarding your proposal. Please contact AUA IRB at [auairb@aua.am](mailto:auairb@aua.am), with a copy to [akopyank@aua.am](mailto:akopyank@aua.am), should you have any questions about the information in this letter. Thank you.

Sincerely,

A handwritten signature in black ink, appearing to read 'Hripsime Martirosyan'.

Hripsime Martirosyan MD, MPH  
Chair, AUA IRB for Clinical Studies  
Senior Clinical Research Coordinator  
Medicus Research LLC, CA, USA

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