Needs and challenges of physicians in the provision of childhood cancer care in Armenia: a qualitative study

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by

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List of abbreviations

ALL	Acute lymphocytic leukemia
AML	Acute myeloid leukemia
HIC	High income countries
LMIC	Low and middle income countries
ICU	Intensive care unit

Abstract

Childhood cancer is an important public health concern worldwide. Globally 2,000,000 new cases of childhood cancer occur per year, 80% of which befall to low- and middle-income countries (LMIC). Moreover, 90% of childhood cancer related deaths occur in LMIC. The available evidence speaks about high percentages of curability and survivorship from childhood cancer in high income countries.

According to the Ministry of Health, the total number of childhood cancer cases registered in Armenia between 2004 and 2013 was 714. The National Center for Oncology after V.A. Fanarjian identified the most common types of childhood cancers in Armenia: hematopoetic and lymphatic system cancers (40%), brain and nervous system cancers (15%), bone tissue malignancies (11%) and kidney cancers (7%) from 2004 to 2014.

Childhood cancer treatment is considered to be difficult and long-lasting. Healthcare professionals are faced with various challenges during the provision of childhood cancer treatment. The literature suggests that insufficient resources for patient care and psychological support, difficulties when providing information to the patients and their families due to emotional aspects, are among the challenges that health care providers deal with.

This qualitative study aims to understand the needs and challenges faced during the provision of pediatric oncology care from the perspective of physicians treating childhood cancer. The study was conducted through semi-structured in-depth interviews with selected study participants. Purposive sampling technique was used for choosing the study participants. The study population included physicians dealing with childhood cancer: a) pediatric hematologists/oncologists, b) radiotherapists, c) pediatric surgeons and d) general chemotherapists. Three study instruments were developed based on the literature review, designed and adapted for the specific groups of respondents for whom they were intended,

and translated into the Armenian language. Data were collected until saturation was reached. Qualitative conventional content analysis method with a deductive approach was used for analyzing the data from the in-depth interviews.

Study findings suggest several needs in the provision of childhood cancer care such as: qualified staff shortages; need for quality trainings for staff especially for pediatric surgeons, pediatrician from ICUs; need for better hospital conditions; and unavailable resources (medication, equipment, cancer registry system) in Armenia. According to the study findings the challenges for physicians in the childhood cancer care delivery included: difficulties in communication with patients and their family members related to the bad news, tiredness, depressions, sleepless nights, heavy workload and inadequate salaries.

1. Introduction

Childhood cancer is one of the public health concerns worldwide. Globally 2,000,000 new cases of childhood cancer occur per year, 80% of which befall to low- and middle-income countries (LMIC).[1] Moreover, 90% of childhood cancer related deaths occur in LMIC.[1] Annually 90,000 children aged <15 years die because of childhood cancer.[2] Pediatric oncology is the second cause of death among children in LMIC.[3] Several studies have shown that genetic and other risk factors (ionizing radiation, exposure to prior chemotherapy, infections from viruses such as Epstein Barr virus, Hepatitis B) can be potential causes of childhood cancer.[4,5] Only 5-15% causes of childhood cancer are due to genetic or familial risk factors that might predispose the child to cancer.[5] Certain exogenous factors and environmental exposures contribute to childhood cancer in 5-10% cases. However, the etiology of childhood cancer is not entirely understood yet.[4,5]

The most common types of childhood cancers worldwide are leukemia and brain tumors.[6] From all childhood cancers, leukemia, including acute lymphocytic leukemia (ALL) and acute myeloid leukemia (AML), accounts for 30%. Brain and spinal cord tumors contribute to 26% of childhood cancers.[7]

The available evidence speaks about high percentages of curability and survivorship from childhood cancer in high income countries (HIC).[8] The five-year childhood cancer survival rate for all cancers increased from 76.1% in 1999 to 79.1% in 2007 in Europe.[8] Another study provides convincing evidence about achievements in treating Wilms tumor (nephroblastoma or kidney cancer in children) in HIC where the survival rate now exceeds 90%.[9]

According to the Ministry of Health of Armenia, the total number of childhood cancer cases registered in Armenia between 2004 and 2013 was 714.[6] The National Center for Oncology after V.A. Fanarjian identified the most common types of childhood cancers in

Armenia from 2004 to 2014.[10] The first most common types of childhood cancers are cancers of the hematopoietic and lymphatic systems (40%), followed by brain and nervous system cancers (15%), bone tissue malignancies (11%) and kidney cancer (7%).[10]

The childhood cancer treatment period is long, lasting from several months to years; it includes chemotherapy, surgery or radiation therapy, depending on the cancer type.[11] Sometimes the child receives a combinations of the above-mentioned treatment methods.[11] During this long and hard treatment process children face a variety of problems.[12] Several studies have been conducted to explore potential problems that pediatric cancer patients have to overcome. One of the studies conducted in Sweden grouped the potential factors influencing cancer care into several categories, including medical treatment and side effects, quality of care, togetherness and support for patients and their isolation.[12] Children reported pain from medical procedures, side effects, eating problems, isolation from activities, isolation from school and physical isolation.[12] A majority of adolescents and children with cancer diagnosis experience cancer-related pains, and the pains are severe, especially at the initial stage of the treatment.[13] In LMICs cancer pain management and control is poor due to failure of physicians' to follow pain management guidelines, physicians' lack of knowledge on opioid pharmacology, physicians' insufficient knowledge on pain assessment, patients' fears from side effects and addiction to the analgesics, the high prices of the necessary opioid analgesics, and limited coverage for medication.[14] During the intense treatment period, children with cancer diagnosis are faced with a variety of psychological and social problems, such as: disruption of normal development; anxiety and depression due to the painful medical procedures and uncertainty of disease outcome; high dependence on family members; and so on.[15] The medical staff dealing with childhood cancer patients needs to provide support to their patients in order to decrease the anxiety of children during the treatment period.[15] There is much that can be done by health care providers to ensure the

full rehabilitative needs of the patients and their families during the provision of cancer care.[15]

A study conducted in Armenia in 2015 provided valuable information about the needs and challenges of Armenian adolescents with cancer diagnosis, and their families.[16] The study revealed that the main challenges in receiving palliative care included inability to pay for treatment, lack of availability of certain drugs, insufficient hospital conditions, lack of psychological counseling services for patients and their families, as well as absence of an opportunity for adolescents to continue their education during the treatment.[16] The author of the conducted research recommended conducting further studies for identification of needs and challenges in pediatric cancer care provision from the perspective of health care providers.[16]

Healthcare professionals are also faced with various challenges during the provision of childhood cancer treatment. The literature suggests that insufficient resources for patient care and psychological support, difficulties when providing information to the patients and their families because of emotional aspects are among the challenges that health care providers deal with.[17] A study conducted in Armenia in 2017 explored the needs and challenges of Armenian pediatric oncology nurses. Among the reported needs and challenges were insufficient hospital conditions, including shortage of drugs and equipment, limited opportunities to enhance nurses' professional knowledge, heavy workload and exhaustion among nurses.[6] Available evidence suggests another challenge that health care professionals face during cancer treatment delivery- communication with patients and their family members. It is very difficult for health providers to inform patients and their family members about cancer diagnosis (delivering the bad news).[18] The main barrier to communication emerges because the family is not ready to know about the cancer diagnosis.[18] Pediatric oncologists act as messengers breaking the bad news on life-

threatening conditions.[14,19] Physicians are alone in the process of informing the family about recurrent disease or transition to palliative care and this is the most difficult challenge for them.[19] The evidence suggests that effective communication and partnership between physicians and their patient's family is paramount. The partnership has the purpose of establishing a feeling of security and confidence, and guaranteeing treatment compliance.[19] During the treatment period, the multidisciplinary team approach, which is the involvement of a wide range of health care professionals in the provision of cancer care, is a commonly used practice.[20] The purpose of these multidisciplinary teams is to improve the communication, decision-making and coordination between health care providers and patients' families.[20] Lack of partnership with the patient's family and absence of multidisciplinary teamwork between different physicians can be considered as one of the reasons for physicians' burnouts and threatened well-being.[19] Other than communication barriers, health care providers also mentioned uncertain prognosis, staff shortage, inadequate knowledge and skills to manage end of life pain, and lack ofexperts in palliative care.[18]

The challenges of pediatric oncology in LMICs are different from HICs. Pediatric oncologists working in LMICs face a shortage of resources (technical equipment, trained medical staff), lack of pediatric cancer registration systems, and lack of qualitytrainings for medical staff.[1,19, 21] Two studies conducted in Armenia identified the main needs and challenges in pediatric cancer care from the perspective of patients and pediatric oncology nurses.[6, 16] The findings include: shortage of trained medical staff, insufficient resources (for technical equipment and expensive medication) for the provision of cancer care, lack of quality trainings for medical staff, which were consistent with the existing literature for LMICs.[6, 16]

Identification of challenges and needs in the provision of pediatric oncological care from the perspective of physicians is an important additional information. This can be an

important contribution to the existing knowledge that could help to develop an action plan for future improvements in pediatric oncology care in Armenia. Adding to the existing studies, a research on the needs and challenges of pediatric oncologists can be valuable for policymakers to develop relevant strategies for improvements in the provision of oncology care. This qualitative study aims to understand the needs and challenges faced during the provision of pediatric oncology care from the perspective of pediatric oncologists.

The research questions are:

1. What are the experiences of physicians dealing with childhood cancer care in Armenia, including pediatric oncologists, oncologists/hematologists, radiotherapists and surgeons?

2. What are the needs and challenges in pediatric cancer care delivery in Armenia from the perspective of physicians dealing with childhood cancer, including pediatric oncologists, oncologists/ hematologists, radiotherapists and surgeons?

3. Methods

2.1 Study design

The qualitative study was conducted through semi-structured in-depth interviews with the selected study participants. This study design is a proper design to gain information on peoples' experiences, perceptions and perspective.[22,23,24] The qualitative research design gave an opportunity to receive rich descriptions about the research questions.[6, 22]

In-depth interviews gave an opportunity to thoroughly explore physicians' experiences, attitudes and elicit their own views about the research questions.[24, 25] Even though in-depth interviews were time intensive, this method of data collection helped to distinguish individuals' opinions separately in a more comfortable and relaxed atmosphere.[25]

2.2 Sampling Strategy

Purposive sampling technique was used for choosing the study population. The purposive sampling strategy helped to explore information-rich cases which have central importance to the purpose of the research.[26] Physicians dealing with childhood cancer patients, including pediatric hematologists/oncologists are people from whom we learnt a great deal about the needs and challenges in the provision of childhood cancer care.

2.3 Study Population

The study team approached three hospitals in Yerevan (the National Center of Oncology after V. A. Fanarjian, the Hematology Center after Professor R. Yeolyan and the "Muratsan" Hospital Complex) and two main hospitals ("Arabkir" medical center and "Sourb Astvatsamayr" medical center) where pediatric cancer patients receive surgical care. Only one of the medical centers refused to participate. The target population included physicians dealing with childhood cancer, with at least six months experience working with pediatric cancer patients - in order to have sufficient experience in pediatric oncology care delivery and be able to respond to the questions. Only physicians with the following specialties dealing with childhood cancer were included in the study: a) pediatric hematologists/oncologists, b) radiotherapists, c) pediatric surgeons and d) general chemotherapist. Data were collected until saturation was reached.

2.4 Study instrument

The socio-demographic information of the study participants was collected before the interview through a short questionnaire (Appendix 1, Appendix 2). The questions related to the participants' social-demographic information were adapted and adopted from a study conducted in Armenia in 2017.[6]

Three study instruments were developed based on literature review, designed and adapted for the specific groups of respondents that they are intended for and translated into Armenian language (Appendices 3 - 8). These are semi-structured interview guides with open-ended questions, allowing to capture the most important, common and urgent challenges and needs in pediatric oncology care delivery. The main domains of the interview guides include information on:

- Experience of physicians treating children with cancer
- Working environment, hospital conditions, relationships with colleagues
- Necessary resources (equipment, drugs, cancer registry) for the provision of pediatric oncology care
- Knowledge gaps/guidelines in pediatric oncology
- Collaboration with other specialists (team approach)
- Communication with the patients and their families
- Physicians' psychological difficulties in the provision of oncology care
- Coping strategies when faced with difficulties
- Suggestions for improvements

The first domain on the experiences of treating children with cancer was adapted from an existing study guide.[6] The questions in the second domain of the interview guide about the working environment, hospital conditions, relationships with colleagues ,[1, 6, 16, 21, 27] the questions of the third domain on the necessary resources,[1,16, 21, 27] and the questions in the fourth domain on the knowledge gaps and guidelines for the provision of childhood cancer care were developed by the student investigator based on several quantitative and qualitative studies.[19, 28-29] The questions related to collaborations with other specialists were developed based on the literature review.[21, 30, 31] In the domain about communication with patients and their family members, some questions were adapted from a study conducted in

Armenia in 2015[16], while others were developed by the student investigator based on several studies.[18,19] The questions about physician's psychological difficulties in the provision of oncology care, coping strategies when facing difficulties, and suggestions for improvements were adapted from other qualitative studies.[6, 16, 19]

2.5 Data collection

After receiving the American University of Armenia Institutional Review Board (IRB) approval, and permission from the heads of oncological and surgical departments, the student investigator started collecting data from study participants. The study participants were informed about the purpose of the study and appropriate times and places were identified for conducting the interviews.

2.6 Data management

Interviews were recorded by an audio-recorder after receiving the participant's permission. Only one participant did not allow recording the interview, thus notes were taken by the interviewer. Each participant had his/her own ID number without any personal identifiers. The recorded data was transcribed in the original language (eight interviews in Armenian language and one interview in Russian language). Data coding was conducted in English, and at the end, the respective quotes were also translated into English. Transcribing the data in the original language (Armenian) ensured that the information provided by the participants was recorded exactly as expressed, without losing any valuable data.

2.7 Data analysis

Qualitative conventional content analysis method with deductive approach was used for analyzing the data from the in-depth interviews. The predetermined themes were based on the literature, there were no new themes emerging from the collected data. From the

transcripts codes were identified by highlighting important meaningful words, phrases and sentences, the codes were gathered into subcategories which identified common patterns emerging from the data.[32, 33]

For ensuring the rigor and trustworthiness of this qualitative study different methods were used. The data collected from different physicians dealing with childhood cancer were triangulated. The triangulation ensured the trustworthiness of the study.[22, 24] The credibility of the study was guaranteed by tactics such as member checks on the spot, which means that throughout the interview the student investigator rephrased responses back to the participant to make sure that a given idea was correctly understood.[34] Another method that was used to ensure the trustworthiness of the study was frequent debriefing sessions with the research team.[34] The examination of previous research findings was also one way to make the study more rigorous, giving an opportunity to assess whether the findings were consistent with the existing literature.[34]

In qualitative research the interviewer is the person who can control the quality of data collection.[35] The student investigator reviewed the literature on interviewing tactics and tips; and followed the existing guidelines related to in-depth interviews in qualitative studies for assuring good quality of data collection.[36] The interviewer developed several important skills, according to the existing in-depth interview guidelines in qualitative studies. The key skill for the interviewer was rapport building, by creating relaxed, positive and mutually respectful atmosphere.[36] The other key skill included highlighting the participant's perspective, as the interviewer's perspective needs to be invisible in the research, otherwise the participants can change their answers to please the interviewer.[36] The interviewer managed the interview effectively by explaining the purpose and the format of the interview to the participant, was very careful to avoid asking the same question twice,

unless the interviewer wanted to verify the response, used probes and avoided using leading questions.[36]

To sustain the credibility of the study results, the interviews were planned to conduct in three hospitals in Armenia providing pediatric cancer treatment and two main hospitals where patients receive surgical care. However, one of the hospitals providing pediatric cancer care refused to participate in the study, thus the data was collected from four health care facilities. This provided an opportunity to avoid the influence of some specific local factors in one hospital on the study findings, and improved the generalizability of the results for four centers.[37]

2.8 Ethical concerns

After receiving the IRB approval from American University of Armenia, the student investigator conducted the in-depth interviews with study participants. An oral consent form (Appendices 9 and 10) was developed to inform participants about the purpose of the study, benefits, and risks and their rights to participate or stop the interview whenever they feel uncomfortable to continue it (participants were informed that their participation was anonymous and recordings would be deleted at the end of the study.

2.9 Categorization of study participants

As the number of study participants was limited, a decision was made by the research team to collapse the four groups of specialists into two to avoid the possibility of them being identified. In order to ensure their anonymity, the respective quotes provided in the results section are presented in coded form, where the pediatric oncologists/hematologists are coded as “oncologists”, while radiotherapists, pediatric surgeons and general chemotherapists are combined under “other specialists”. However,

this only applies to the quotes themselves, while the summaries in the results section provide analysis for all four specialists.

3. Results

3.1 Socio-demographic characteristics of participants

The data through in-depth interviews was collected from four pediatric oncologist/hematologists, two radiotherapists, two pediatric surgeons and one general chemotherapist who worked with pediatric cancer cases. All interviews were conducted in the hospitals and one interview was conducted at Yerevan State Medical University. The mean duration of in-depth interviews was 50 minutes. In one hospital, physicians refused to participate in the study because of shortage of time.

The mean age of physicians was 40 years and the range was between 30 and 68. The mean duration of professional experience was 14 years (Table 1).

3.2 Attitude towards profession

3.2.1. Advantages and disadvantages of being a physician treating childhood cancer

Almost all interviewed physicians mentioned that they like their profession and highlighted the advantages of being physicians treating childhood cancer. The majority of the participants mentioned the fast developing scientific field as an advantage of their profession, while almost all participants emphasized that cured children are always inspiring them and are therefore the advantage of their profession. Another advantage reported by all physicians was the effectiveness of the treatment. Pediatric surgeons indicated that pediatric onco-surgery demands special training and high professionalism for performing the required surgeries. Although pediatric surgeons considered these surgeries as difficulties in their

profession, they also stated that these help increase the professionalism of a surgeon, which is the advantage of performing a difficult job. For some physicians, working in an interesting and broad field was considered as an advantage, while for some others working with children and helping children was.

It is an advantage that you realize that as a surgeon you are specially trained. Not everyone is ready to work in this field. This is not a pleasant field, because you know that your patient does not have a favorable prognosis. However, you decide to continue on with them, even though the outcome can be bad.

3.2.1 Other specialist

Radiation Oncology is a very interesting field. It is connected with adjacent sciences like physics, IT technologies…

3.2.1. Other specialist

A few decades ago the probability of being cured was 0%, today it is 70%. We have a big opportunity to cure children. Pediatric oncology is a rapidly developing field. This is the first advantage [of working in this field]*, the second is that I like working with children.*

3.2.1. Oncologists

When you see cancer-free patients 20 years later, who according to all rules should not be alive, and yet have a prosperous life with their children … this is the advantage for me.

3.2.1. Oncologist

The disadvantages of being a physician treating childhood cancer were mainly connected with financial problems, heavy workload, inadequate salary, unavailable resources and psychosocial difficulties. The pediatric oncologists' opinions were triangulated with pediatric surgeons' and radiotherapists' opinions.

In addition, one of the radiotherapists mentioned that radiation therapy is not applicable for children younger than three, which is a disadvantage in the field of radiation therapy.

Our work is psychologically and physically hard and it does not finish after leaving the hospital. You reach home, but you continue getting calls and conduct consultations through social networks. We are completely engaged in work our entire life, yet we do not receive appropriate salaries. That is a big issue.

3.2.1. Oncologist

A physician must remember that he/she is a physician and must not be emotional, but we are only human, it happens. We mustn't be emotional; our patients need professionalism rather than emotions.

3.2.1. Other specialist

3.2.2. About the difficulty of the profession

It is commonly believed that being a physician treating childhood cancer is more difficult compared to other medical specializations. The participants' views about this statement were different. Some physicians stated that in their opinion this field is much more difficult compared to others, while others did not want to differentiate medical specializations according to their difficulty, and highlighted that each medical specialization has its difficulties. Participants who indicated that the field is more difficult underlined the psychological burden of the profession, the heavy workload, the fact that sometimes it was impossible to separate the job from personal life, and working with less informed and educated parents as the main issues. Pediatric surgeons considered that performing oncological surgeries on children demanded special training and not everyone wanted to perform such hard surgeries. However, some participants stated that if one decided to enter

the medical field and become a physician, then they had to be prepared to face the difficulties it entails.

My job has a strong connection with life. I cannot separate my job from my personal life, because we communicate with patients for a long time and they become our family members.

3.2.2. Oncologist

We share responsibility with parents, especially for those parents who are not informed, less educated, less literate. It is difficult; we have to become part time parents for the child, because we know what we do and why we do it.

3.2.2. Other specialist

Of course pediatric oncology is a difficult profession, but there are other [difficult] medial professions also, such as pediatric intensive care. Every field has its particularities and difficulties. If you chose to become a physician you have to take all these into consideration.

3.2.2. Oncologist

Pediatric onco-surgery is a more difficult field, because the probability of complications during surgeries is higher, and it is very difficult to understand the volume of the surgery.

3.2.2. Other specialist

3.2.3 Physicians' health and profession

As mentioned previously, working with childhood cancer patients can have an impact on the physicians' health. All participants talked about the psychological and physical difficulties that they faced during the provision of childhood cancer care; starting from tiredness and sleepless nights to depressions and changes in attitude towards life. Participants explained that those physicians who work with pediatric cancer patients may sometimes be perceived as cold people, when the reality is completely different; it's just that they do not have a right to lose themselves from the emotional and psychological aspects. For physicians the highest value of life is an individual's health and well-being. However,

regardless of these health problems, almost all physicians agreed that the physicians' health problems should not affect cancer care provision.

Our work is very stressful and our attitude towards life is entirely different, with completely different values. Health is not just a word… when you lose a child during your night-shift, your values change. To you a good brand of car, a watch, or a telephone do not exist. You are only thinking about peoples' health.

3.2.3. Oncologist

Bad [referring to the impact of working with childhood cancer patients], *of course bad… tiredness, sometimes depressions, sleepless nights… Our health problems mustn't have an effect on the provision of care. That is why it is commonly believed that physicians are cold people. This isn't true; it's just that we cannot afford to lose ourselves.*

3.2.3. Other specialist

3.3 Teamwork and patients' health

3.3.1 Working environment and relationships between colleagues in the team

The majority of the participants emphasized that the working environment at their departments are healthy and relationships between colleagues are highly collaborative and productive. Some of the interviewed physicians mentioned that good relationships and a positive working environment have a positive effect by increasing the productivity of a physician's work and allowing them to develop as a specialist. Under the concept of "team", physicians indicated their specific departments with its physicians and nurses. The majority of the doctors described their team as a united big family where all members have their unique role and importance. From the physicians' point of view, the role of pediatric oncology nurses is huge in the team. The main belief was that patients always benefit thanks to the warm atmosphere in the team and joint efforts of colleagues. The overwhelming majority of the physicians highlighted that patients always belong to the

entire team, as there is no differentiation as to whose patient they are. All doctors take care of all patients and the decisions on treatment tactics are made by the entire team, thus guaranteeing successful treatment through this team approach. Although some of the participants thought that sometimes disagreements between colleagues could have an impact on care, nobody could bring a specific example. The majority of the participants stated that colleagues may have some disagreements within the team, but these disagreements are easily resolved by the team.

We are very united and we help each other a lot, we do not have any problems in our relationships.

3.3.1. Oncologist

A good working atmosphere leads to an increase in productivity, as when the atmosphere is good everyone wants to work better. At our clinic we always follow a team approach… The patients belong to the team and teamwork creates a sense of safety among patients and their families.

3.3.1. Other specialist

3.3.2 Collaborations with other specialists while providing childhood cancer care

It is a well-known fact that cancer treatment demands a multidisciplinary team approach and all physicians treating childhood cancer follow this approach. All participants mentioned the significance of collaborating with other specialists. The majority of the physicians highlighted that these collaborations were vital and very helpful. An interesting thing reported was that specialists treating childhood cancer created a "Tumor Board" which is a team meeting when specialists from different fields gather together to discuss a patient's case. According to the participants, collaborations with specialists from various fields, such as, cardiologists, nephrologists, traumatologists, surgeons, dietician, anesthesiologists, and

others was inevitable, because the process of treatment of childhood cancer was filled with risks of possible complications, making the help of other specialists paramount. All physicians emphasized the role and importance of psychologists in providing supportive counselling not only to children, but also parents. All interviewed physicians indicated that the hospitals where they work have at least one psychologist.

Some doctors expressed their concerns related to the shortage of some specialists in the team, which is discussed in detail under the "resources" subheading. It was unanimously agreed that all aspects of cancer care benefited from teamwork.

Pediatric oncology demands a multidisciplinary team approach all over the world.

3.3.2. Oncologist

We have created "Tumor Boards", where various specialists discuss patient cases, treatment tactics and so on with each other.

3.3.2. Other specialist

We are working with psychologists trained abroad in the field of onco-psychology. They help us a lot.

*3.3.2.*Oncologist

Pediatric surgeon, radiologist, radiotherapist, pediatric orthopedist in case of bone tumors; this is a big team that treats childhood cancer. The cooperation of various specialists is very important for receiving modern results.

3.3.2. Oncologist

Chemotherapy is a very difficult treatment and we are often faced with various complications, such as endocrine, cardiac, nephrological and so on. That is why all specialists play a great role.

3.3.2. Oncologist

Sometimes psychological support is needed not only for patients, but for their parents as

well. It is possible that the patient's family needs more psychological support than the patient themselves.

3.3.2. Other specialist

Finally, after years of discussion now we have a psychologist at our hospital, she just started to work at the department, I hope she [psychologist] will help patients, family members [patients'] and us [medical staff].

3.3.2. Other specialist

3.4 Resources

3.4.1. Hospital conditions

According to participants, hospital conditions play some role in provision of childhood cancer care, but it is not crucial and does not have any direct impact on cancer care. The participants repeatedly mentioned that good hospital conditions can create psychological comfort for both patients and medical staff. Almost all physicians estimated the state of the buildings where they work as adequate for providing cancer care. Only one participant mentioned that the state of the building was "wonderful", which was limited to one floor only, where children receive chemotherapy. Two participants from the same hospital reported that their hospital was being renovated. Physicians from other hospitals indicated that the department needed to be renovated and enlarged as the number of patients exceeded the space in the department, which could create risks of infections due to overcrowded wards.

Now conditions are [hospital conditions in pediatric chemotherapy department] wonderful. Previously the conditions in the department were terrible, but even in those terrible conditions the patient rooms for children were comparatively better than those for adults.

3.4.1. Other specialist

Of course we would like to have better hospital conditions. It would create comfort for patients, their family members, physicians and medical staff.

3.4.1. Other specialist

We have sufficient state of building and it is going to be better. For instance, the seventh floor is renovated; that's the chemotherapy department.

3.4.1. Other specialist

The state of our building is not appropriate for surgical stationary, but it is maximally adapted. I would not say that the state of the building can have a direct impact on treatment outcomes.

3.4.1. Other specialist

If the patient sees the whole work and results of the treatment, the state of the building becomes secondary.

3.4.1. Other specialist

We would like to have bigger space for our department, because the number of patients is more than the number of patient rooms. Sometimes some patients need single rooms. For example, if the patient has leukemia he/she cannot be protected from infections, so contact with other people must be limited.

3.4.1. Oncologist

3.4.2 Resources for provision of childhood cancer care

Participants unanimously highlighted that the training of specialists providing childhood cancer care was very important and effective for provision of cancer care. Almost all participants reported that they received training courses. Moreover, a majority of the physicians mentioned that practically all physicians in their departments attended trainings very frequently.

Most participants mentioned that they had all the essential equipment for provision of childhood cancer care, but they need to have more equipment and more modern, renewed

ones. Pediatric cancer treatment is expensive, and physicians reported that charitable foundations helped children receiving expensive treatments. The role of charitable foundations is huge in the provision of childhood cancer care. Among the charitable foundations they mentioned "Ognem", "Nvirir kyanq", "Bridge of Health" and some others, which help children with cancer receive the majority of the chemotherapeutic medications.

All physicians in our department are trained abroad, one goes another one comes.

3.4.2. Oncologist

Our department has expensive, modern equipment. Of course, medical technologies advance and there will be better equipment. Of course, we would like to have the new ones [equipment] *and more…*

3.4.2. Other specialist

To be honest we haven't had patients who were deprived of receiving treatment because of lack of money. Charitable Foundations help children a lot.

3.4.2. Other specialist

Charitable foundations play a great role in pediatric cancer care delivery. For example, "Nvirir kyanq", "Ognem" or "Bridge of health" and other foundations help us obtain the majority of the required medication.

3.4.2.Oncologist

One of the physicians mentioned that they needed social workers at their hospital. The pediatric oncologists and a pediatric surgeon mentioned the shortage of pediatric onco-surgeons and highlighted the importance of special trainings to perform such surgeries. There is a shortage of pediatricians with experience in working in intensive care units specialized in the field of pediatric oncology. Radiotherapists highlighted about the shortage of radiotherapists, physicists, technicians. Pediatric oncologists indicated about the shortage of pediatric oncologists and pediatric oncology nurses.

Besides the shortages of specialists in the team, participants mentioned about the lack of high quality pediatric oncology services located in a single hospital. Pediatric oncology patients receive different kinds of treatments in different hospitals, for instance chemotherapy is delivered in chemotherapy clinic, radiation therapy is delivered at National Oncology Center and so on. This creates various problems for patients.

We do not have trained pediatric oncology nurses. They [referring to the nurses they have] *previously worked with adults and then because of the need* [for nurses] *they started to work with children.*

3.4.2. Other specialist

I would like to see physicians from intensive care units trained in the field of onco-hematology. They are all very skillful physicians, but intensive care is different in the field of onco-hematology.

3.4.2. Oncologist

At our clinic [hospital where patient receives surgical care] we do not have social workers, oncologists, radiotherapists. The problem is that patients receive different kinds of treatments [radiotherapy, surgery, chemotherapy] at different hospitals.

3.4.2. Other specialist

The problem with the medication required for chemotherapy is connected to their cost and licensing. Pediatric oncologists indicated that hospitals have small quantities of essential medication provided by the government. Besides these, patients receive the rest of the required medication, which are more expensive, through support from charitable foundations. There are some medications which are not registered in Armenia and for obtaining these medications the patients' family members face a variety of problems. In

addition, charitable foundations provide tremendous help for gaining only essential medications, hospitals do not have up to date medications.

There are very important medications which are not registered in Armenia.

3.4.2. Other specialist

Thanks to the charitable foundations we can get medications, but only essential medication, we do not have up to date medications, because they are very expensive and not available.

3.4.2. Oncologist

Medication is very expensive. We receive small quantities of some medication provided by the government…, this is a big issue. We would like to receive all medication through the governmental support, but we understand that it will be difficult, because the required medication are very expensive.

3.4.2. Oncologist

We have another big issue connected to medication. There are some medication, which are not registered in Armenia and it is understandable why, as these are very expensive and we might only need them twice a year. However, there is no statistics on how frequently we may need them, so we should have them [not registered medication] … The medication is not registered, so we end up having to talk to family members and try to find other ways of obtaining them, because in oncology time never waits for anybody.

3.4.2. Oncologist

Although all of the pediatric oncologists stated that they have all essential equipment, a problem emerged with the application of high doses Methotrexate medication, due to the lack of equipment. Radiotherapists mentioned that they have shortage of equipment and the department needs more. Pediatric surgeons highlighted the absence of a "Frozen Section" method, which creates a lot of technical problems. The "Frozen Section" procedure is a commonly used method in oncological surgeries when during the surgical

procedure intraoperatively taken specimen needs to be examined by the pathologist for preliminary histological and/or cytological diagnosis while surgery is still in progress. Performing "Frozen Section" saves time for both the surgeon and the patient. The surgeons explained that since such pathological laboratories at surgical departments are absent in Armenia, it takes some time to send the specimen to another hospital and then receive the result of histological and/or cytological analysis. Only after receiving the pathological histological analysis results can the surgeon decide to continue or stop the surgical procedure.

In Armenia we cannot prescribe high dosage of Methotrexate, because we do not have the essential equipment… For the past 30 years, 5 grams of Methotrexate is being used worldwide, but in Armenia we cannot. If this problem were solved we would not propose children to receive radiation therapy, which is not advisable.

3.4.2. Oncologist

In Armenia there is no frozen section concept, no immediate answer for histological analysis, you can perform the surgery and again repeat it, because of the absence of the method [for an immediate histological testing]… During the surgery I give the tissue to a caregiver and they take it to the "Davidyants" clinic. About 40-60 minutes after the histological analysis, the pathologists gives me the answer, and only after that does the surgeon understands the future process of surgery. The "Frozen Section" method provides an opportunity to receive the answer earlier, because the pathologist is located near the surgical room.

3.4.2. Other specialist

All the physicians treating childhood cancer stated that there was no complete cancer registry, although there was an initiative to create a cancer registry. According to the participants, an incomplete cancer registry did not have a direct impact on treatment

outcomes, but it limited the understanding of the real picture of statistics and monitoring of patient outcomes.

There is no complete cancer registry. So we do not have real statistical data. Besides that, we have lost to follow up and future monitoring of patients is very difficult.

3.4.2. Other specialist

The lack of complete cancer registry does not have any direct influence on treatment, but if we will have cancer registry we would understand a lot. If you start to register something it becomes easy to manage the situation. We would have precise statistical data; we would not have loss to follow up.

3.4.2. Oncologist

3.5 Knowledge in the field of pediatric oncology

As it was mentioned previously, the field of pediatric oncology is a fast developing field and knowledge gaps exist. Pediatric oncologists and pediatric surgeons highlighted the existing knowledge gaps, while radiotherapists stated that there were no knowledge gaps in the provision of radiation therapy. All participants emphasized the importance and need of enhancing knowledge in the field of pediatric oncology and stated that they always make efforts to acquire new knowledge in order to follow modern science. They mentioned numerous sources of up-to-date information, including: trainings and conferences abroad; paper based and electronic medical literature; and discussions with Armenian and international colleagues.

Of course there is a knowledge gap in pediatric oncology. This problem exists in Europe, USA and of course in Armenia as well. It is inevitable [referring to acquiring new knowledge]. Physicians must be up to date.

3.5. Oncologist

[Sources of information include] *Medical literature, conferences, trainings, telemedicine… all physicians can easily collaborate with physicians abroad… If a physician stops reading and gaining knowledge, they will fall behind from reality and modern science.*

3.5. Other specialist

Knowledge of English language is very important, because all normal books are in English. Internet resources help a lot, but you need to know what you are reading, from where, whether it is a reliable source or not…. It is very important that we all received training in different countries like USA, France, Russia, and Great Britain. We collect all these experiences, and discuss them with each other to enhance our knowledge and apply those experiences in Armenia.

3.5. Other specialist

Study participants highlighted some problems that they faced for enhancing knowledge. Some participants mentioned that they were very busy all day and didn't have time for self-development. Some of the physicians complained about the financial burden of trainings and costly access to literature. .

We do not have access to modern literature, books are very expensive… we try to read electronic versions, but often new editions of books become available one or two years later.

3.5.Other specialist

First of all the willingness to enhance knowledge is the most important. For international conferences, fellowships, training courses the barrier is the lack of financial support.

3.5. Other specialist

Physician must receive appropriate salary; it is impossible to work only based on enthusiasm. Physicians shouldn't have to think about other jobs [to earn more money] and should concentrate on work. This would help with self-development.

3.5. Oncologist

As a physician you have to do a lot of things, which can actually be done by others. This overloads us… paper work, helping parents to obtain medications… how can you find time for reading after an overloaded working day?

3.5. Other specialist

3.5.1. Importance of pediatric oncology guidelines

All physicians highlighted the importance of pediatric oncology guidelines. There was triangulation between responses from pediatric oncologists and those from radiotherapists and pediatric surgeons. Physicians stated that they all work according to the internationally accepted guidelines (there are no guidelines for Armenia yet) and the results of using these guidelines are positive. During data collection some of the pediatric oncologists notified that the Ministry of Health of Republic of Armenia is currently working on pediatric oncology guidelines and soon certain guidelines will be available. According to pediatric oncologists if the case was difficult and steps of guideline were not definitely applicable, physicians would discuss and reach a decision as a team.

Of course we always follow the guidelines they are applicable and adapted for Armenia, this helps to provide good quality of care.

3.5.1. Other specialist

Unfortunately, there can be some cases when protocols cannot be fully applied, so we all discuss future tactics of treatment as a team.

3.5.1. Oncologist

We cannot create the schemes or guidelines in Armenia and there is no need to invent a bicycle, because we have evidence based effective working treatment scheme. We just need to apply it.

3.5.1. Oncologist

Currently, the Ministry of Health is working on guidelines of pediatric oncology, I think they

will not make us wait for long; soon we will have certain guidelines accepted by the Ministry of Health.

3.5.1. Oncologist

3.6 Psychology of patient-physician relationships

3.6.1. Good, honest patient-physician relationships and communication

All of the study participants highlighted the importance of good communication and relationships between the physician, the patient and their family. A majority of the physicians described pediatric oncology care as a collaboration between the patient, the patient's family and the treating physician. According to physicians' point of view this collaboration must be organized in an effective way to reach successes in treatment outcomes. Participants mentioned that those physicians working with children have to be good psychologists. The main step for establishing good communication and a trustful relationship was an honest and friendly atmosphere. Some of the physicians highlighted the importance of communicating with the child, regardless of the patient's age.

Communication and collaboration with patients is very important, because treatment is collaboration between the patient, his/her family and the treating physician… If the collaboration is good the relationships becomes more trustful and you can reach success in treatment…. You mustn't lie to children; you have to be honest with a child. He/she [patient] must feel that you [physician] are open with them. Regardless of the age the child must feel that you treat him/her as an adult. You explain the situation directly to the child rather than a parent. This helps a lot. In this case they are ready to do anything you ask them.

3.6.1. Other specialist

If you are working with children, you have to have a deep knowledge of children's psychology. Pediatric cancer patients need a more gentle approach, you must inspire them, give them power. Psychological support provided by the physician is a very important

factor.

3.6.1. Other specialist

If you have a friendly attitude towards the parents, if the atmosphere is trustful, then they accept you and they understand that whatever the physician does is only for their child's benefit.

3.6.1. Oncologist

3.6.2. Difficulties in patient-physician relationship and coping strategies

According to the physicians, communicating with patients and their family members was not easy. Every interviewed physician highlighted that the most difficult part in patient-physician relationships and communication connected with providing information to parents about the bad news related to dangerous diagnosis or life threating situations. Physicians described this experience as the most painful part of their job. They explained that sometimes parents want to hear magical news from the physicians, but physicians have to kill the parents' and patients' last hope, which is a terrible situation for them. Relapses of the disease, low chances for survival and loss of the patients were described as awful pain that physician have to bear silently. Despite all difficulties, physicians mentioned that they had to inform parents and children about the diagnosis because it was unavoidable. Physicians highlighted that lack of awareness among parents and the psychological situation of the parent makes communication difficult. The majority of physicians reported that there was nothing universal to help them overcome these difficulties. Some of the participants emphasized the unique role of cured children as a source of inspiration and coping strategy.

The most difficult part is that you have to inform about the disease, features of the disease, you need to thoroughly explain the treatment process, evaluate chances for survival and expectations from treatment. You just have to tell them [patients and patient's family members] the information which they do not want to listen.

3.6.2. Other specialist

They [patients and patient's family members] all have the last hope that something is wrong in the diagnosis and as a physician you have to kill their last hope. It is painful, it hurts… You cannot do anything, you have to be a professional at your work and bear the pain silently; simply you do not have a right to be emotional.

3.6.2. Other specialist

Often parents want the impossible. It is very difficult to tell that we cannot operate because it is too late, that even if they lose their property we will still be unable to save their child's life. They always have a last hope that if the surgeon operates, the child will survive. It is difficult to explain that there are no possibilities…the physician is an ordinary person, not God. It is very hard, believe me.

3.6.2. Other specialist

When a patient comes with relapse, or when the treatment was not effective, or when we lose a patient, it seems like unbearable pain.

3.6.2. Oncologist

It is very difficult when medicine is powerless and you cannot do anything. Or when medicine is not powerless and there are possibilities to treat the child abroad, but the family cannot afford it.

3.6.2. Oncologist

It is very difficult to inform about bad news, especially for Armenian families, where a child is equal to God. It is extremely hard when a family loses their only child… it is very difficult to inform parents. You have to provide information by small doses, step by step you have to choose the most appropriate words to tell the truth and at the same time try alleviate the pain. These conversations can last days. This is the most difficult part of our job.

3.6.2. Oncologist

The most difficult thing is that parents are not informed and you have to explain all

information and then work with them to find drugs, to listen that they do not have money. Every moment is a struggle… There is nothing universal; there is no formula to explain how you can cope with these difficulties.

3.6.2. Other specialist

Coping? [the difficulties faced] It just seems that you overcome the difficulties through long years of experience. I do not agree that time heals, it never helped me. The pain is the same, it never gets easy… maybe the communication in difficult situation becomes more effective, as experience helps us improve our communication skills. Sometimes when you think of the big army of children who survived cancer, maybe this gives you some inspiration to overcome the difficulties.

3.6.2. Oncologist

3.7 Suggestions for improvements

Almost all suggestions for improvements in the field of pediatric oncology were related to the necessary support from the government and other donor agencies. The biggest problems were related to lack of financial support and unavailable resources. Almost all participants mentioned about the lack of knowledge related to pediatric cancer among parents and physicians providing primary care. All suggestions indicated possible ways to resolve these problems and enhance the quality of pediatric cancer care provision in Armenia. Among the possible solutions they mentioned financial support to receive trainings. One of the participants mentioned that in Armenia there are no competent pediatric oncologists and suggested finding competent people and organizing quality trainings abroad for them.

I would like to see financial support from the government. Annually we have 60-80 cases and with the big willingness it is possible to provide more resources to these patients. Patients and their families must get governmental support, social services and psychological services.

3.7. Oncologist

I would like to get financial support for trainings abroad.

3.7. Other specialist

If the financial support will be available we can solve all the problems. We have potential, education, specialists… we can solve the problems. We have power, enthusiasm and willingness to make pediatric cancer care better. We just need financial resources.

3.7. Other specialist

I cannot say that currently we have competent pediatric oncologists in Armenia, so we need financial support and competent people who will go abroad and will bring experiences here for creating a pediatric oncology service.

3.7. Other specialist

It is very important to take pediatric oncologists' point of view into consideration. Also, the number of incompetent people in the field must be reduced, or their roles be removed.

3.7. Oncologist

I would like to say one word- financing. Government must alleviate the financial burden of the treatment, there is a need to solve the problem with registering of drugs, to make all needed testing maximally available, to solve the problem of unavailable resources and make the service cheap, fast and accessible. Moreover, it is very important to increase the level of awareness among patients and physicians providing primary care.

3.7. Oncologist

For instance social workers could help us [with paperwork].

3.7. Other Specialist

There was an interesting suggestion to create societies for patients, for instance society of cancer survivors. Some other suggestions were about appropriate salaries for physicians and making medical literature more available. One of the participants

highlighted about the need of social workers for helping them to solve the problems with paperwork.

Physician must have an incentive; we all know that once the "white coat romance" fades after 5, 10 or 20 years, only the material aspect [money] remains. Someone has to inspire the physician, maybe the government…

3.7. Oncologist

In Armenia there is no concept of networking. The society of cancer survivors can play a great role; it will be useful for patients and for physicians as well….I would like to have access to literature which is quite costly.

3.7. Other specialist

4. Discussion

The conducted study was the first study in Armenia that explored physicians' perspective on needs and challenges in the provision of childhood cancer care. The evidence we found pointed to the fact that physicians treating children with cancer had a special attitude towards their profession. The majority of participants highlighted various advantages of being a physician treating childhood cancer. Although, dealing with children who have cancer creates many psychological and physical difficulties for physicians, they are devoted to their job, and the children they cure are the biggest source of their inspiration. Despite the challenging job, the majority of participants were satisfied with their job. The existing literature suggests that job satisfaction and positive attitude towards the profession of treating children with cancer increases the productivity of the work and increases the quality of provided care.[38] A study conducted in Poland found that health care professionals who treat children with cancer had the highest level of job satisfaction and this had a potential to contribute to the improvement of quality of provided care.[38]

Physicians participating in the study reported experiencing depression, anxiety, stress, exhaustion, tiredness and sleepless nights during their professional life. However, they unanimously stated that their health problems should not affect cancer care provision. This fact lends support to previous findings in the literature where pediatric oncologists reported about work-related psychological and physical difficulties during their professional life.[39,40]

The study participants emphasized the importance of collaboration with colleagues and reported about the "Tumor Boards" that they had created with the purpose to collaborate with various specialists. Teamwork plays a great role in cancer care delivery. It is commonly believed that cancer care demands multidisciplinary approach and collaboration of various medical specialists.[41]

The study conducted in 2015 highlighted the need of psychologists in hospitals providing oncology care in Armenia.[16] In 2018, we have documented a positive change which indicates that all four hospitals, two of which previously participated in the 2015 research, currently hired psychologists to work with children.

The study participants highlighted the major role of pediatric oncology nurses in care and indicated that there was a shortage of pediatric oncology nurses; this finding is consistent with a previous study conducted in Armenia in 2017.[6] In LMIC, shortage of trained pediatric oncology nurses is one of the major challenges.[42]

The study findings suggested an unmet need of trained anesthesiologists and physicians in intensive care units. Moreover, the study participants mentioned about the shortage of trained pediatric surgeons in their team performing oncological surgeries. According to the internationally accepted guidelines the role of physicians in intensive care units and anesthesiologists with expertise in the management of children is crucial.[41]

As in other LMIC, in Armenia the resources for provision of pediatric oncology care are limited. Although two previous studies conducted in Armenia indicated insufficient hospital conditions, the majority of the study participants graded hospital conditions as sufficient.[6,16] In LMIC problems related to the lack or shortage of trained medical staff is one of the challenges in the provision of good care, while in Armenia physicians indicated about the existing twinning programs, quality trainings abroad, but these opportunities were only for physicians and they were limited because of financial issues.[6,43] Even though physicians had some opportunities for trainings, pediatric surgeons, ICU physicians, anesthesiologists and pediatric oncology nurses did not get appropriate opportunities for special trainings. Although majority of the study participants mentioned that they were receiving quality trainings continuously one of the participants took under the doubt the fact of having competent people in Armenia in the field of pediatric oncology.

A study conducted among Armenian adolescents with cancer diagnosis in 2015 identified the inability to pay for treatment as the main problem for pediatric cancer care.[16] According to the participants of this study, this problem was solved thanks to major contributions from charitable foundations in Armenia. However, the problem related to medication not registered in Armenia still remained problematic.[6,16] Unavailability of certain chemotherapeutic drugs, equipment, cancer registry are common issues in LMIC.[1,6,16,43] Lack of cancer registry in Armenia did not allow to have precise statistical data and monitor patients appropriately. Although study participants mentioned that the hospitals had the most essential equipment, the problem with the shortage of modern equipment remained unsolved.

According to the study participants, knowledge gaps in the field of pediatric oncology remained problematic and there was a need to update the information and acquire new knowledge. Besides the gaps in the field of pediatric oncology, physicians reported an

existing knowledge gap among physicians who provided primary care. The available evidence suggests that in LMIC one of the factors contributing to delayed diagnosis is the lack of knowledge of general physicians about pediatric cancer.[44] Several studies have shown that the knowledge of parents about the signs and symptoms of disease is very limited.[44,45] Lack of knowledge leads to underdiagnosis of the disease which decreases patients' chances for survival.[1,43] The study participants reported the same issue related to the poor knowledge of parents on pediatric oncological diseases.

In pediatric oncology all physicians have to follow guidelines on pediatric oncology treatment.[1] Although there were no existing guidelines in the Armenian language, the study participants reported following internationally accepted guidelines. Some of the participants mentioned the ongoing process of acceptance of pediatric oncology guidelines by the Ministry of Health of the Republic of Armenia.

The importance of physician-patient relationships and communication was highlighted by the participants of the study. Physicians working with children indicated the importance of understanding children's psychology, in order to establish good communication and relationship with them. Good, honest, trustful patient-physician relationship and communication could strengthen the effective collaboration between the patient and treating physician for fighting the disease. The most difficult part in this collaboration has become informing parents and patients about the diagnosis. Evidence from the existing literature supports the fact that physicians treating children with cancer act as messengers in life threatening situations and that is a very difficult part of their work.[19]

Armenian pediatric oncology nurses reported sharing their feelings and emotions with colleagues and friends as a coping strategy,[6] while physicians indicated that there was nothing universal that could help them to overcome the psychological difficulties in their

daily work. Some of the participants highlighted the role of cured children in overcoming the psychological problems and frequent meetings with teams outside of the hospital.

4.1 Study strengths and limitations

The study which explored the needs and challenges during the provision of childhood cancer care from the perspective of physicians, was the first study conducted in Armenia with participation of pediatric oncologist/hematologists, pediatric surgeons, radiotherapists and general chemotherapist treating childhood cancer. The study gave an opportunity to add knowledge regarding the issue and to look at the problem from the perspectives of a different stakeholder group. The involvement of pediatric oncologists and other specialists helped ensure triangulation and enhance the rigor of the study; moreover, multicenter study which was conducted in four hospitals increased the generalizability of the results.

Physicians from one of the hospitals providing pediatric cancer care refused to participate in a study, so the number of eligible participants decreased. The possibility of data collection from physicians of this hospital would have added rigor to the study, as we would have the whole picture of the field.

4.2 Recommendations

The study findings suggest that there is a variety of problems that should be solved in order to provide better quality of care improving hospital conditions and access to medications in Armenia. The governmental support for solving these problems related to lack of resources is paramount.

Based on the study findings and literature review, the research team made/makes the following recommendations:

- Support physicians in gaining knowledge by providing financial support for attending quality trainings abroad, or creating opportunities to invite international experts in the field of pediatric oncology to Armenia for training the local providers.
- Create training opportunities for pediatric surgeons, physicians from ICUs and pediatric oncology nurses, as physicians participating in a study mentioned about the need of trainings for these specialists.
- Provide psychological counselling services for physicians and training on communication and counseling skills for physicians for the purpose of alleviating the burden of breaking the news about the disease and its prognosis.

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Table 1 Characteristics of participants

Characteristics	N
Age, Mean (Range)	**40.0 (30.0-68.0)**
Gender	
Male	**4**
Female	**5**
Profession	
Pediatric Oncologist/Hematologist	**4**
Radiotherapist	**2**
Pediatric Surgeon	**2**
General Chemotherapist	**1**
Total number of participants	**9**
Mean years of experience	
Pediatric Oncologist/Hematologist	**19.0**
Radiotherapist	**19.5**
Pediatric Surgeon	**10.5**
Mean years of experience for all participants (Range)	**14.0 (4.0-32.0)**

Appendix 1

Questionnaire for the study participant

Please respond to the following questions by writing on the provided line or circling the correct answer.

1. Your age (completed years) _____

2. Your gender
   a) Male
   b) Female

3. Your specialization
   a) Pediatric oncologist
   b) Hematologist/ Oncologist
   c) Radiotherapist
   d) Pediatric surgeon

4. How many years have you worked with your specialization with children who have cancer? _____ years

Appendix 2

Հարցաթերթիկ հետազոտության մասնակցի համար

Պատասխանե՛ք խնդրեմ հետևյալ հարցերին՝ օղակի մեջ վերցնելով ճիշտ պատասխանը կամ գրելով նախատեսված տողում:

1. Ձեր տարիքը _____

2. Ձեր սեռը
   ա) արական
   բ) իգական

3. Ձեր մասնագիտացումը
   ա) մանկական ուռուցքաբան
   բ) մանկական արյունաբան/ ուռուցքաբան
   գ) ռադիոթերապևտ
   դ) մանկական վիրաբույժ

4. Քանի՞ տարի եք աշխատել Ձեր մասնագիտությամբ բուժելով մանկական քաղցկեղը _____ տարի

Appendix 3

In depth interview guide for pediatric oncologists and hematologist/oncologists

The experience of treating children with childhood cancer

1. Could you please tell me how you decided to become a physician treating childhood cancer and what was the motivation?
2. Could you please tell me about your job? (Probes: Do you like your job? What is it like to be a physician who treats childhood cancer? How has your job affected your life? In your opinion, is being a physician treating childhood cancer and working with children with cancer more difficult compared to other medical specializations?)
3. What are the advantages and disadvantages of being a pediatric oncologist?

Working environment and relationship with colleagues

4. How would you describe the working environment at your workplace? How does the working environment affect childhood cancer care delivery?
5. In your opinion, how important are good relationships between colleagues? How can these relationships affect patient treatment? (Probe: Could you please share any examples that you have personally experienced or heard of, either at your hospital or elsewhere, when relationship issues between colleagues have affected care delivery?)

Necessary resources (hospital infrastructure, equipment, drugs, cancer registry) for the provision of pediatric oncology care

6. How would you describe the hospital conditions (physical state of the building) where you are working currently? (Probe: How would you grade the hospital conditions?) In your opinion, how do these conditions affect the provision of pediatric oncology care?
7. Would you please describe the current situation concerning resources at the hospital where you work? (Probe: number of trained specialists, equipment, drugs, cancer registry). How could the number of trained specialists, equipment, drugs and lack of cancer registry

influence oncology treatment? What would you suggest to improve the situation? (Probe: what resources are required for the provision of pediatric oncology care at your hospital?)

8. From your perspective what are the main challenges that physicians have to overcome to ensure good quality childhood cancer care?

Knowledge of pediatric oncology

9. In your opinion are there any knowledge gaps in this field? How can knowledge gaps influence cancer treatment? What sources of information are available to you? (Probe: Are discussions with colleagues, literature review, attending conferences and trainings helpful in addressing these knowledge gaps?) What additional activities could be done to provide more opportunities for improving physicians' knowledge?

10. How important are the pediatric oncology guidelines for health care providers for you as a physician? How does adhering to existing guidelines affect cancer care delivery?

Collaboration with other specialists (team approach)

11. Would you please tell me about your collaborations with other medical specialists, nurses or psychologists throughout the pediatric oncology care delivery period? From your perspective how important is this collaboration? (Probe: Do you find it useful?) Which aspects of care could particularly benefit from team work? What kind of specialists do you need during the teamwork?

Communication with the patients and their families

12. What is your opinion about the patient-physician communication and relationship?

13. Could you please describe how you establish good communication and relationships with patients and their family members?

14. What is the most difficult part of communication with patients and their family members? How do you overcome these difficulties? Who/what can help you during this communication?

Physicians' psychological difficulties in the provision of oncology care, coping strategies when facing difficulties and suggestions for improvement

15. Could you please describe the affect that dealing with children who have cancer has on your health? (Probe: What kind of difficulties do you face?) Do you think these difficulties can influence pediatric oncology care delivery? If so, how?
16. Could you please describe how or thanks to whom you cope with difficulties and challenges during your work? What can be done to alleviate some of these difficulties and challenges? (Changes in regulations, procedures, what kind of support, etc)

Additional question

17. Are there any additional suggestions you may have for the improvement of pediatric oncology care delivery in Armenia?

Thank you for participation

Appendix 4

In depth interview guide for radiotherapists

The experience of treating children with childhood cancer

1. Could you please tell me how you decided to become a physician treating childhood cancer and what was the motivation?
2. Could you please tell me about your job? (Probes: Do you like your job? What is it like to be a physician who treats childhood cancer? How has your job affected your life? In your opinion, is being a physician treating childhood cancer and working with children with cancer more difficult compared to other medical specializations?)
3. What are the advantages and disadvantages of being a radiotherapist who treats children with cancer?

Working environment and relationships with colleagues

4. How would you describe the working environment at your workplace? How does the working environment affect childhood cancer care delivery?
5. In your opinion, how important are good relationships between colleagues? How can these relationships affect patient treatment? (Probe: Could you please share any examples that you have personally experienced or heard of, either at your hospital or elsewhere, when relationship issues between colleagues have affected care delivery?)

Necessary resources (hospital infrastructure, equipment, drugs, cancer registry) for the provision of pediatric oncology care

6. How would you describe the hospital conditions (physical state of the building) where you are working currently? (Probe: How would you grade the hospital conditions?). In your opinion, how do these conditions affect the provision of pediatric oncology care?
7. Would you please describe the current situation concerning resources for provision of radiotherapy at the hospital where you work? (Probe: number of trained specialists, equipment, drugs, cancer registry). How could the number of trained specialists, equipment,

drugs and lack of cancer registry influence oncology treatment? What would you suggest to improve the situation? (Probe: what resources are required for the provision of pediatric oncology care at your hospital?)

8. From your perspective what are the main challenges that physicians have to overcome to ensure good quality childhood cancer care?

Knowledge of pediatric oncology

9. In your opinion are there any knowledge gaps in this field? How can knowledge gaps influence cancer treatment (radiation therapy)? What sources of information are available to you? (Probe: Are discussions with colleagues, literature review, attending conferences and trainings helpful in addressing these knowledge gaps?) What additional activities could be done to provide more opportunities for improving physicians' knowledge?

10. How important are the pediatric oncology guidelines for health care providers for you as a physician? How does adhering to existing guidelines affect cancer care (radiation therapy) delivery?

Collaboration with other specialists (team approach)

11. Would you please tell me about your collaborations with other medical specialists, nurses or psychologists throughout the pediatric oncology care delivery period? From your perspective how important is this collaboration? (Probe: Do you find it useful?) Which aspects of care could particularly benefit from team work? What kind of specialists do you need during the teamwork?

Communication with the patients and their families

12. What is your opinion about the patient-physician communication and relationship?

13. Could you please describe how you establish good communication and relationships with patients and their family members?

14. What is the most difficult part of communication with patients and their family members? How do you overcome these difficulties? Who/what can help you during this communication?

Physicians' psychological difficulties in the provision of oncology care, coping strategies when facing difficulties and suggestions for improvement

15. Could you please describe the affect that dealing with children who have cancer has on your health? (Probe: What kind of difficulties do you face?) Do you think these difficulties can influence pediatric oncology care delivery? If so, how?

16. Could you please describe how thanks to whom you cope with difficulties and challenges during your work? What can be done to alleviate some of these difficulties and challenges? (Changes in regulations, procedures, what kind of support, etc)

Additional question

17. Are there any additional suggestions you may have for the improvement of pediatric oncology care delivery in Armenia?

Thank you for participation

Appendix 5

In depth interview guide for pediatric oncologists and hematologist/oncologists

The experience of treating children with childhood cancer

1. Could you please tell me how you decided to become a physician treating childhood cancer and what was the motivation?
2. Could you please tell me about your job? (Probes: Do you like your job? What is it like to be a physician who treats childhood cancer? How has your job affected your life? In your opinion, is being a physician treating childhood cancer and working with children with cancer more difficult compared to other medical specializations?)
3. What are the advantages and disadvantages of being a pediatric oncologist?

Working environment and relationship with colleagues

4. How would you describe the working environment at your workplace? How does the working environment affect childhood cancer care delivery?
5. In your opinion, how important are good relationships between colleagues? How can these relationships affect patient treatment? (Probe: Could you please share any examples that you have personally experienced or heard of, either at your hospital or elsewhere, when relationship issues between colleagues have affected care delivery?)

Necessary resources (hospital infrastructure, equipment, drugs, cancer registry) for the provision of pediatric oncology care

6. How would you describe the hospital conditions (physical state of the building) where you are working currently? (Probe: How would you grade the hospital conditions?) In your opinion, how do these conditions affect the provision of pediatric oncology care?
7. Would you please describe the current situation concerning resources at the hospital where you work? (Probe: number of trained specialists, equipment, drugs, cancer

registry). How could the number of trained specialists, equipment, drugs and lack of cancer registry influence oncology treatment? What would you suggest to improve the situation? (Probe: what resources are required for the provision of pediatric oncology care at your hospital?)

8. From your perspective what are the main challenges that physicians have to overcome to ensure good quality childhood cancer care?

Knowledge of pediatric oncology

9. In your opinion are there any knowledge gaps in this field? How can knowledge gaps influence cancer treatment? What sources of information are available to you? (Probe: Are discussions with colleagues, literature review, attending conferences and trainings helpful in addressing these knowledge gaps?) What additional activities could be done to provide more opportunities for improving physicians' knowledge?
10. How important are the pediatric oncology guidelines for health care providers for you as a physician? How does adhering to existing guidelines affect cancer care delivery?

Collaboration with other specialists (team approach)

11. Would you please tell me about your collaborations with other medical specialists, nurses or psychologists throughout the pediatric oncology care delivery period? From your perspective how important is this collaboration? (Probe: Do you find it useful?) Which aspects of care could particularly benefit from team work? What kind of specialists do you need during the teamwork?

Communication with the patients and their families

12. What is your opinion about the patient-physician communication and relationship?
13. Could you please describe how you establish good communication and relationships with patients and their family members?

14. What is the most difficult part of communication with patients and their family members? How do you overcome these difficulties? Who/what can help you during this communication?

Physicians' psychological difficulties in the provision of oncology care, coping strategies when facing difficulties and suggestions for improvement

15. Could you please describe the affect that dealing with children who have cancer has on your health? (Probe: What kind of difficulties do you face?) Do you think these difficulties can influence pediatric oncology care delivery? If so, how?
16. Could you please describe how or thanks to whom you cope with difficulties and challenges during your work? What can be done to alleviate some of these difficulties and challenges? (Changes in regulations, procedures, what kind of support, etc)

Additional question

17. Are there any additional suggestions you may have for the improvement of pediatric oncology care delivery in Armenia?

Thank you for participation

Appendix 6

Հարցազրույցի ուղեցույց մանկական ուռուցքաբանների և արյունաբան/ուռուցքաբանների համար

Մանկական քաղցկեղը բուժելու փորձառությունը

1. Կպատմե՞ք, թե ինչպես որոշեցիք դառնալ մանկական քաղցկեղ բուժող բժիշկ: Ո՞րն էր Ձեր մոտիվացիան:

2. Կպատմե՞ք Ձեր աշխատանքի մասին: (Դուք սիրու՞մ եք Ձեր աշխատանքը: Ի՞նչ է նշանակում լինել բժիշկ, ով բուժում է քաղցկեղով հիվանդ երեխաներին: Ինչպե՞ս է դա անդրադառնում Ձեր կյանքի վրա: Ըստ Ձեզ՝ մանկական ուռուցքաբանի, արյունաբան/ուռուցքաբանի մասնագիտությունն ավելի՞ բարդ է, քան այլ բժիշկ մասնագետներինը:)

3. Որո՞նք են մանկական ուռուցքաբան/արյունաբան լինելու առավելություններն ու թերությունները:

Աշխատանքային միջավայրը և հարաբերությունները կոլեգաների հետ

4. Ինչպե՞ս կնկարագրեք աշխատանքային միջավայրը Ձեր աշխատավայրում: Ինչպե՞ս է աշխատանքային միջավայրն անդրադառնում մանկական քաղցկեղի բուժումն իրականացնելու վրա:

5. Ձեր կարծիքով որքանո՞վ են կարևոր լավ հարաբերությունները կոլեգաների միջև: Ինչպե՞ս կարող են այս հարաբերություններն ազդել մանկական քաղցկեղի բուժում տրամադրելու վրա: (Կբերե՞ք որևէ օրինակ, որը պատահել է անձամբ Ձեզ կամ մեկ ուրիշի հետ՝ ձեր կամ մեկ այլ

հիվանդանոցում, երբ կոլեգաների միջև առաջացած խնդիրները անդրադարձել են մանկական քաղցկեղի բուժման վրա)

Անհրաժեշտ ռեսուրսներ (հիվանդանոցի ներքին կառուցվածքը, սարքավորումներ, դեղորայք և քաղցկեղի ռեգիստրացիոն համակարգ և այլն) մանկական քաղցկեղի բուժման տրամադրման համար

6. Ինչպե՞ս կնկարագրեք հիվանդանոցային (շենքային) պայմանները, որտեղ ներկայումս աշխատում եք: (Ինչպե՞ս եք գնահատում հիվանդանոցային պայմանները: Ձեր կարծիքով, ինչպե՞ս կարող են բավարար կամ անբավարար հիվանդանոցային պայմաններն անդրադառնալ մակական քաղցկեղի բուժումն իրականացնելու վրա:)

7. Կնկարագրե՞ք ռեսուրները այն հիվանդանոցում՝ որտեղ աշխատում եք (վերապատրաստված մասնագետների թիվը, սարքավորումներ, դեղորայք, քաղցկեղի ռեգիստրացիոն համակարգ): Ինչպե՞ս են վերապատրաստված մասնագետների, անհրաժեշտ սարքավորումների, դեղորայքի թիվը և քաղցկեղի ռեգիստրացիոն համակարգի բացակայությունն ազդում քաղցկեղի բուժման վրա): Ի՞նչ կառաջարկեք իրավիճակը բարելավելու համար: (Խնդրում եմ նկարագրե՛ք այն անհրաժեշտ ռեսուրսները, որոնց կարիքն ունեք մանկական քաղցկեղի բուժումն իրականացնելու համար:)

8. Ձեր կարծիքով՝ որո՞նք են այն հիմնական մարտահրավերները, որ բժիշկը պետք է հաղթահարի որակյալ բուժում տրամադրելու քաղցկեղով հիվանդ երեխաներին:

Գիտելիքը մանկական ուռուցքաբանության ոլորտում

9. Ձեր կարծիքով, կա արդյո՞ք գիտելիքի բաց մանկական ուռուցքաբանության ոլորտում: Ինչպե՞ս կարող է այս գիտելիքի բացն ազդել մանկական քաղցկեղի բուժման վրա: Որո՞նք են ինֆորմացիայի այն աղբյուրները, որոնք օգնում են լրացնել գիտելիքի բացը: (Արդյո՞ք կոլեգաների հետ քննարկումները, բժշկական գրականության ուսումնասիրությունը, գիտաժողովները, վերապատրաստման դասընթացները օգնու՞մ են լրացնելու գիտելիքի բացը): Ձեր կարծիքով, ի՞նչ կարող է արվել, որպեսզի բժիշկներն ունենան ավելի շատ հնարավորություններ գիտելիքների հարստացման համար:

10. Որպես բժիշկ՝ որքանո՞վ եք կարևորում մանկական քաղցկեղի բուժման ուղեցույցները: Ինչպե՞ս կարող է ուղեցույցներին հետևելը կամ չհետևելը անդրադառնալ մանկական քաղցկեղի բուժման վրա:

Համագործակցություն այլ մասնագետների հետ (թիմային մոտեցում)

11. Կպատմե՞ք Ձեր և այլ բժիշկ-մասնագետների, բուժքույրերի կամ հոգեբանների հետ համագործակցությունից: Ձեր կարծիքով՝ որքա՞ն կարևոր է այլ մասնագետների հետ համագործակցությունը մանկական քաղցկեղի բուժման ամբողջ ընթացքում: (Օգտակար համարու՞մ եք այս համագործակցությունը): Բուժման ո՞ր ասպեկտներն են հատկապես շահում թիմային աշխատանքից: Ի՞նչ մասնեգետների կարիք կա թիմային աշխատանքի ժամանակ:

Հաղորդակցումը հիվանդի և հիվանդի ընտանիքի հետ

12. Ինչպիսի՞ կարծիք ունեք բժիշկ-հիվանդ հաղորդակցման և հարաբերությունների մասին:

13. Կնկարագրե՞ք, խնդրեմ, թե ինչպես եք լավ հաղորդակցություն և լավ հարաբերություններ հաստատում հիվանդի և նրա ընտանիքի անդամների հետ:

14. Ո՞րն է հիվանդի և նրա ընտանիք անդամների հետ հաղորդակցման ամենաբարդ փուլը: Ինչպե՞ս եք հաղթահարում հաղորդակցման դժվարությունները: Ի՞նչը/ո՞վ կարող է օգնել այս հաղորդակցության ժամանակ:

Քաղցկեցի բուժման ընթացում բժիշկների հանդիպած բարդությունները, դժվարությունների հաղթահարման մեթոդներ և բարեփոխումների առաջարկներ

15. Կնկարագրե՞ք թե ինչպես է մանկական քաղցկեղով հիվանդ երեխաներին բուժելն անդրադառնում Ձեր առողջության վրա: (Ինչպիսի՞ բարդությունների եք բախվում մանկական քաղցկեղի բուժում տրամադրելու ընթացում): Ի՞նչ եք կարծում, կարո՞ղ են այս դժվարություններն ազդել մանկական քաղցկեղի բուժման ընթացքի վրա: Եթե այո, ապա՝ ինչպե՞ս:

16. Կնկարագրե՞ք, թե ինչպես կամ ու՞մ միջոցով կարելի է հաղթահարել այս դժվարություններն ու մարտահրավերները Ձեր ամենօրյա աշխատանքում: Ի՞նչ կարելի է անել այդ դժվարություններն ու մարտահրավերները մեղմացնելու համար: (փոփոխություններ կանոնակարգերի, պրոցեդուրաների մեջ, ինչպիսի՞ աջակցություն է անհրաժեշտ)

Լրացուցիչ հարց

17. Ունե՞ք որևէ լրացուցիչ առաջարկ՝ Հայաստանում մանկական քաղցկեղի բուժումը բարելավելու համար:

Appendix 7

Հարցազրույցի ուղեցույց ռադիոթերապևտների համար

Մանկական քաղցկեղը բուժելու փորձառությունը

1. Կպատմե՞ք, թե ինչպես որոշեցիք դառնալ մանկական քաղցկեղ բուժող բժիշկ: Ո՞րն էր Ձեր մոտիվացիան:

2. Կպատմե՞ք Ձեր աշխատանքի մասին: (Դուք սիրու՞մ եք Ձեր աշխատանքը: Ի՞նչ է նշանակում լինել բժիշկ, ով բուժում է քաղցկեղով հիվանդ երեխաներին: Ինչպե՞ս է դա անդրադառնում Ձեր կյանքի վրա: Ըստ Ձեզ՝ լինել բժիշկ ով բուժում է մանկական քաղցկեղով հիվանդներին ավելի՞ բարդ է ի համեմատ այլ բժիշկ մասնագետների հետ:)

3. Որո՞նք են ռադիոթերապևտ լինելու առավելություններն ու թերությունները:

Աշխատանքային միջավայրը և հարաբերությունները կոլեգաների հետ

4. Ինչպե՞ս կնկարագրեք աշխատանքային միջավայրը Ձեր աշխատավայրում: Ինչպե՞ս է աշխատանքային միջավայրն անդրադառնում մանկական քաղցկեղի ճառագայթային բուժումն իրականացնելու վրա:

5. Ձեր կարծիքով որքանո՞վ են կարևոր լավ հարաբերությունները կոլեգաների միջև: Ինչպե՞ս կարող են այս հարաբերություններն ազդել մանկական քաղցկեղի ճառագայթային բուժում տրամադրելու վրա: (Կբերե՞ք որևէ օրինակ, որը պատահել է անձամբ Ձեզ կամ մեկ ուրիշի հետ՝ ձեր կամ մեկ այլ հիվանդանոցում, երբ կոլեգաների միջև առաջացած խնդիրները անդրադարձել են մանկական քաղցկեղի բուժման վրա)

<u>Անհրաժեշտ ռեսուրսներ (հիվանդանոցի ներքին կառուցվածքը, սարքավորումներ, դեղորայք և քաղցկեղի ռեգիստրացիոն համակարգ և այլն) մանկական քաղցկեղի բուժման տրամադրման համար</u>

6. Ինչպե՞ս կնկարագրեք հիվանդանոցային (շենքային) պայմանները, որտեղ ներկայումս աշխատում եք: (Ինչպե՞ս եք գնահատում հիվանդանոցային պայմանները): Ձեր կարծիքով, ինչպե՞ս կարող են բավարար կամ անբավարար հիվանդանոցային պայմաններն անդրադառնալ մակական քաղցկեղի ճառագայթային բուժումն իրականացնելու վրա):

7. Կնկարագրե՞ք ռեսուրները այն հիվանդանոցում՝ որտեղ աշխատում եք: (վերապատրաստված մասնագետների թիվը, սարքավորումներ, դեղորայք, քաղցկեղի ռեգիստրացիոն համակարգ): Ինչպե՞ս են վերապատրաստված մասնագետների, անհրաժեշտ սարքավորումների, դեղորայքի թիվը և քաղցկեղի ռեգիստրացիոն համակարգի բացակայությունն ազդում քաղցկեղի բուժման վրա): Ի՞նչ կառաջարկեք իրավիճակը բարելավելու համար: (Խնդրում եմ նկարագրե՛ք այն անհրաժեշտ ռեսուրսները, որոնց կարիքն ունեք մանկական քաղցկեղի բուժումն իրականացնելու համար:)

8. Ձեր կարծիքով՝ որո՞նք են այն հիմնական մարտահրավերները, որ բժիշկը պետք է հաղթահարի որակյալ բուժում տրամադրելու քաղցկեղով հիվանդ երեխաներին:

Գիտելիքը մանկական ուռուցքաբանության ոլորտում

9. Ձեր կարծիքով, կա արդյո՞ք գիտելիքի բաց մանկական ուռուցքաբանության ոլորտում ճառագայթային բուժման վերաբերյալ: Ինչպե՞ս կարող է այս գիտելիքի բացն ազդել մանկական քաղցկեղի բուժման վրա: Որո՞նք են ինֆորմացիայի այն աղբյուրները, որոնք օգնում են լրացնել գիտելիքի բացը: (Արդյո՞ք կոլեգաների հետ քննարկումները, բժշկական գրականության ուսումնասիրությունը, գիտաժողովները, վերապատրաստման դասընթացները օգնու՞մ են լրացնելու գիտելիքի բացը): Ձեր կարծիքով, ի՞նչ կարող է արվել, որպեսզի բժիշկներն ունենան ավելի շատ հնարավորություններ գիտելիքների հարստացման համար:

10. Որպես բժիշկ՝ որքանո՞վ եք կարևորում մանկական քաղցկեղի բուժման ուղեցույցները: Ինչպե՞ս կարող է ուղեցույցներին հետևելը կամ չհետևելը անդրադառնալ մանկական քաղցկեղի բուժման վրա:

Համագործակցություն այլ մասնագետների հետ (թիմային մոտեցում)

11. Կպատմե՞ք Ձեր և այլ բժիշկ-մասնագետների, բուժքույրերի կամ հոգեբանների հետ համագործակցությունից: Ձեր կարծիքով՝ որքա՞ն կարևոր է այլ մասնագետների հետ համագործակցությունը մանկական քաղցկեղի բուժման ամբողջ ընթացքում: (Օգտակար համարու՞մ եք այս համագործակցությունը): Բուժման ո՞ր ասպեկտներն են հատկապես

շահում թիմային աշխատանքից: Ի՞նչ մասնեգետների կարիք կա թիմային աշխատանքի ժամանակ:

Հաղորդակցումը հիվանդի և հիվանդի ընտանիքի հետ

12. Ինչպիսի՞ կարծիք ունեք բժիշկ-հիվանդ հաղորդակցման և հարաբերությունների մասին: Որքանո՞վ է դա կարևոր Ձեզ համար:

13. Կնկարագրե՞ք խնդրեմ, թե ինչպես եք լավ հաղորդակցություն և լավ հարաբերություններ հաստատում հիվանդի և նրա ընտանիքի անդամների հետ:

14. Ո՞րն է հիվանդի և նրա ընտանիքի անդամների հետ հաղորդակցման ամենաբարդ փուլը: Ինչպե՞ս եք հաղթահարում հաղորդակցման դժվարությունները: Ի՞նչը/ո՞վ կարող է օգնել այս հաղորդակցության ժամանակ:

Քաղցկեցի բուժման ընթացում բժիշկների հանդիպած բարդությունները, դժվարությունների հաղթահարման մեթոդներ և բարեփոխումների առաջարկներ

15. Կնկարագրե՞ք թե ինչպես է մանկական քաղցկեղով հիվանդ երեխաներին բուժելն անդրադառնում Ձեր առողջության վրա: (Ինչպիսի՞ բարդությունների եք բախվում մանկական քաղցկեղի բուժում տրամադրելու ընթացում): Ի՞նչ եք կարծում, կարո՞ղ են այս

դժվարություններն ազդել մանկական քաղցկեղի բուժման ընթացքի վրա: Եթե այո, ապա՝ ինչպե՞ս:

16. Կնկարագրե՞ք, թե ինչպես կամ ու՞մ միջոցով կարելի է հաղթահարել այս դժվարություններն ու մարտահրավերները Ձեր ամենօրյա աշխատանքում: Ի՞նչ կարելի է անել այդ դժվարություններն ու մարտահրավերները մեղմացնելու համար: (փոփոխություններ կանոնակարգերի, պրոցեդուրաների մեջ, ինչպիսի՞ աջակցություն է անհրաժեշտ)

Լրացուցիչ հարց

17. Ունե՞ք որևէ լրացուցիչ առաջարկ՝ Հայաստանում մանկական քաղցկեղի բուժումը բարելավելու համար:

Շնորհակալություն մասնակցության համար

Appendix 8

Հարցազրույցի ուղեցույց մանկական վիրաբույժների համար

Մանկական քաղցկեղը բուժելու փորձառությունը

1. Կպատմե՞ք, թե ինչպես որոշեցիք դառնալ բժիշկ, մանկական քաղցկեղը բուժող բժիշկ, ով վիրահատում է մանկական քաղցկեղով հիվանդ երեխաներին: Ո՞րն էր Ձեր մոտիվացիան:

2. Կպատմե՞ք Ձեր աշխատանքի մասին, երբ բուժում եք մանկական քաղցկեղով հիվանդ երեխաներին: (Դուք սիրու՞մ եք Ձեր աշխատանքը: Ի՞նչ է նշանակում լինել բժիշկ, ով բուժում է քաղցկեղով հիվանդ երեխաներին: Ինչպե՞ս է դա անդրադառնում Ձեր կյանքի վրա: Ըստ Ձեզ՝ լինել վիրաբույժ ով վիրահատում է մանկական քաղցկեղով հիվանդներին ավելի՞ բարդ է ի համեմատ այլ բժիշկ մասնագետների հետ:)

3. Որո՞նք են մանկական վիրաբույժ լինելու առավելություններն ու թերությունները:

Աշխատանքային միջավայրը և հարաբերությունները կոլեգաների հետ

4. Ինչպե՞ս կնկարագրեք աշխատանքային միջավայրը Ձեր աշխատավայրում: Ինչպե՞ս է աշխատանքային միջավայրն անդրադառնում մանկական քաղցկեղի վիրահատական բուժումն իրականացնելու վրա:

5. Ձեր կարծիքով որքանո՞վ են կարևոր լավ հարաբերությունները կոլեգաների միջև: Ինչպե՞ս կարող են այս հարաբերություններն ազդել

մանկական քաղցկեղի վիրաբուժական բուժում տրամադրելու վրա: (Կբերե՞ք որևէ օրինակ, որը պատահել է անձամբ Ձեզ կամ մեկ ուրիշի հետ՝ ձեր կամ մեկ այլ հիվանդանոցում, երբ կոլեգաների միջև առաջացած խնդիրները անդրադարձել են մանկական քաղցկեղի բուժման վրա)

Անհրաժեշտ ռեսուրսներ (հիվանդանոցի ներքին կառուցվածքը, սարքավորումներ, դեղորայք և քաղցկեղի ռեգիստրացիոն համակարգ և այլն) մանկական քաղցկեղի բուժման տրամադրման համար

6. Ինչպե՞ս կնկարագրեք հիվանդանոցային (շենքային) պայմանները, որտեղ ներկայումս աշխատում եք: (Ինչպե՞ս եք գնահատում հիվանդանոցային պայմանները): Ձեր կարծիքով, ինչպե՞ս կարող են բավարար կամ անբավարար հիվանդանոցային պայմաններն անդրադառնալ մակական քաղցկեղի վիրահատական բուժումն իրականացնելու վրա:)

7. Կնկարագրե՞ք ռեսուրները այն հիվանդանոցում՝ որտեղ աշխատում եք: (վերապատրաստված մասնագետների թիվը, սարքավորումներ, դեղորայք, քաղցկեղի ռեգիստրացիոն համակարգ): Ինչպե՞ս են վերապատրաստված մասնագետների, անհրաժեշտ սարքավորումների, դեղորայքի թիվը և քաղցկեղի ռեգիստրացիոն համակարգի բացակայությունն ազդում քաղցկեղի բուժման վրա): Ի՞նչ կառաջարկեք իրավիճակը բարելավելու համար: (Խնդրում եմ նկարագրե՛ք այն անհրաժեշտ ռեսուրսները, որոնց կարիքն ունեք մանկական քաղցկեղի բուժումն իրականացնելու համար:)

8. Ձեր կարծիքով՝ որո՞նք են այն հիմնական մարտահրավերները, որ բժիշկը պետք է հաղթահարի որակյալ բուժում տրամադրելու քաղցկեղով հիվանդ երեխաներին:

Գիտելիքը մանկական ուռուցքաբանության ոլորտում

9. Ձեր կարծիքով, կա արդյո՞ք գիտելիքի բաց մանկական ուռուցքաբանության ոլորտում վիրահատական բուժման վերաբերյալ: Ինչպե՞ս կարող է այս գիտելիքի բացն ազդել մանկական քաղցկեղի բուժման վրա: Որո՞նք են ինֆորմացիայի այն աղբյուրները, որոնք օգնում են լրացնել գիտելիքի բացը: (Արդյո՞ք կոլեգաների հետ քննարկումները, բժշկական գրականության ուսումնասիրությունը, գիտաժողովները, վերապատրաստման դասընթացները օգնու՞մ են լրացնելու գիտելիքի բացը): Ձեր կարծիքով, ի՞նչ կարող է արվել, որպեսզի բժիշկներն ունենան ավելի շատ հնարավորություններ գիտելիքների հարստացման համար:

10. Որպես բժիշկ՝ որքանո՞վ եք կարևորում մանկական քաղցկեղի բուժման ուղեցույցները: Ինչպե՞ս կարող է ուղեցույցներին հետևելը կամ չհետևելը անդրադառնալ մանկական քաղցկեղի բուժման վրա:

Համագործակցություն այլ մասնագետների հետ (թիմային մոտեցում)

11. Կպատմե՞ք Ձեր և այլ բժիշկ-մասնագետների, բուժքույրերի կամ հոգեբանների հետ համագործակցությունից: Ձեր կարծիքով՝ որքա՞ն կարևոր է այլ մասնագետների հետ համագործակցությունը մանկական քաղցկեղի բուժման ամբողջ ընթացքում: (Օգտակար համարու՞մ եք այս համագործակցությունը): Բուժման ո՞ր ասպեկտներն են հատկապես շահում թիմային աշխատանքից: Ի՞նչ մասնեգետների կարիք կա թիմային աշխատանքի ժամանակ:

Հաղորդակցումը հիվանդի և հիվանդի ընտանիքի հետ

12. Ինչպիսի՞ կարծիք ունեք բժիշկ-հիվանդ հաղորդակցման և հարաբերությունների մասին: Որքանո՞վ է դա կարևոր Ձեզ համար:

13. Կնկարագրե՞ք, խնդրեմ, թե ինչպես եք լավ հաղորդակցություն և լավ հարաբերություններ հաստատում հիվանդի և նրա ընտանիքի անդամների հետ:

14. Ո՞րն է հիվանդի և նրա ընտանիք անդամների հետ հաղորդակցման ամենաբարդ փուլը: Ինչպե՞ս եք հաղթահարում հաղորդակցման դժվարությունները: Ի՞նչը/ո՞վ կարող է օգնել այս հաղորդակցության ժամանակ:

Քաղցկեցի բուժման ընթացում բժիշկների հանդիպած բարդությունները, դժվարությունների հաղթահարման մեթոդներ և բարեփոխումների առաջարկներ

15. Կնկարագրե՞ք թե ինչպես է մանկական քաղցկեղով հիվանդ երեխաներին բուժելն անդրադառնում Ձեր առողջության վրա: (Ինչպիսի՞ բարդությունների եք բախվում մանկական քաղցկեղի բուժում տրամադրելու ընթացում): Ի՞նչ եք կարծում, կարո՞ղ են այս դժվարություններն ազդել մանկական քաղցկեղի բուժման ընթացքի վրա: Եթե այո, ապա՝ ինչպե՞ս:

16. Կնկարագրե՞ք, թե ինչպես կամ ու՞մ միջոցով կարելի է հաղթահարել այս դժվարություններն ու մարտահրավերները Ձեր ամենօրյա աշխատանքում:

Ի՞նչ կարելի է անել այդ դժվարություններն ու մարտահրավերները մեղմացնելու համար: (փոփոխություններ կանոնակարգերի, պրոցեդուրաների մեջ, ինչպիսի՞ աջակցություն է անհրաժեշտ)

Լրացուցիչ հարց

17. Ունե՞ք որևէ լրացուցիչ առաջարկ՝ Հայաստանում մանկական քաղցկեղի բուժումը բարելավելու համար:

Շնորհակալություն մասնակցության համար

Appendix 9

Consent form for physicians (English version) American University of Armenia Institutional Review Board #1

Consent form

"Needs and challenges of physicians in the provision of childhood cancer care in Armenia: A qualitative study"

Hello, my name is Saten. I graduated from Yerevan State Medical University and now I am a second year graduate student at Gerald and Patricia Turpanjian School of Public Health at the American University of Armenia. School of Public Health is conducting a study to explore the experiences of physicians treating childhood cancer, and the needs and challenges in the provision of pediatric oncology treatment in Armenia.

You are invited to participate in this study, as you are a registered (*pediatric oncologist, oncologist/hematologist, radiotherapist, pediatric surgeon)* who treats children with cancer and works in one of the Oncology Hospitals in Yerevan. Your contact information has been obtained from the department where you work. Your participation in this study is limited to this single interview, which will last up to one hour. Your participation in this study is voluntary. There is no penalty if you refuse to participate in the study, it will not affect your work in any way. You may skip any question if you do not want to answer or you can stop the interview at any time you want.

Your participation in this study will contribute to better understanding of the challenges and needs of pediatric cancer care delivery in Armenia and will help to suggest appropriate strategies and solutions to overcome the problems. The information provided by

you during the interview will be confidential and will be used for the study purposes only. Only the research team will have access to this information. Your name or other contact information will not be mentioned anywhere in the final report, and only some quotes will be presented in the general findings without indicating your name or other information that could trace back to you. After receiving your permission I will record our interview to not miss any important information that you provide. However, if you feel uncomfortable with this, then it is perfectly within your rights to ask me to turn off the recorder at any time during the interview. If you have any questions regarding this study you can ask me or you can contact the Dean of the School of Public Health, Dr. Varduhi Petrosyan at (060) 61 25 92. If you feel you have been hurt by joining the study or you have not been treated fairly, you can contact the AUA Human Subject Protection Administrator, Varduhi Hayrumyan, (060) 61 25 61. If you agree to participate could we continue?

Do you agree to audio-recording?

Appendix 10

Հայաստանի Ամերիկյան Համալսարան Հանրային առողջապահության ֆակուլտետ

Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով

Իրազեկ համաձայնության ձև

Հայաստանում մանկական քաղցկեղի բուժման կարիքներն ու խնդիրները ըստ քաղցկեղը բուժող բժիշկների

Բարև Ձեզ, իմ անունը Սաթեն է: Ես ավարտել եմ Երևանի պետական բժշկական համալսարանը և այժմ սովորում եմ Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության մագիստրոսական ծրագրի ավարտական կուրսում: Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետը իրականացնում է հետազոտություն, որի նպատակն է հետազոտել մանկական քաղցկեղը բուժող բժիշկների փորձառությունները և մանկական ուռուցքների բուժման ընթացքում հանդիպող խնդիրներն ու կարիքները՝ բժիշկների տեսանկյունից:

Դուք հրավիրված եք մասնակցելու այս հետազոտությանը, քանի որ Դուք մանկական քաղցկեղը բուժող բժիշկ եք և աշխատում եք (մանկական ուռուցքաբան/արյունաբան, ռադիոթերապևտ, մանկական վիրաբույժ) Երևանի ուռուցքաբանական հիվանդանոցներից մեկում: Ձեր կոնտակտային տվյալները վերցվել են այն բաժնից, որտեղ Դուք աշխատում եք: Ձեր մասնակցությունը այս հետազոտությանը կամավոր է: Եթե Դուք հրաժարվեք մասնակցել հետազոտությանը, դա որևէ բացասական հետևանք չի ունենա և որևէ կերպ չի

անդրադառնա Ձեր աշխատանքի վրա: Ձեր մասնակցությունն այս հետազոտությանը սահմանափակվում է մեկ հարցազրույցով, որը կարող է տևել մինչև մեկ ժամ՝ Ձեզ հարմար ժամին և վայրում: Հարցազրույցի ընթացքում ես կուղղեմ Ձեզ հարցեր, որոնք վերաբերում են՝ մանկական քաղցկեղը բուժելու Ձեր փորձառությանը, աշխատանքային միջավայրին և կոլեգաների հետ հարաբերություններին, մանկական քաղցկեղի բուժման համար անհրաժեշտ ռեսուրսներին, մանկական ուռուցքաբանության գիտելիքներին, այլ մասնագետների հետ համագործակցությանը, հիվանդների և նրանց ընտանիքի անդամների հետ հաղորդակցմանը, Ձեր հոգեբանական բարդություններին մանկական քաղցկեղով երեխաներին բուժելիս, բարդությունների հաղթահարման մեխանիզմներին և առաջարկներ մանկական քաղցկեղի բուժումը բարելավելու մասին: Դուք կարող եք հրաժարվել պատասխանել ցանկացած հարցի կամ ընդհատել հարցազրույցը ցանկացած պահի: Ձեր մասնակցությունն այս հետազոտությանը չի ներառում որևէ ուղղակի օգուտ Ձեզ համար: Ձեր մասնակցությունը այս հետազոտությանը շատ կարևոր է մեզ համար: Այն կօգնի մեզ ճիշտ պատկերացում կազմել մանկական քաղցկեղի բուժման ընթացքում առաջացող խնդիրների և կարիքների մասին և կօգնի առաջարկել հնարավոր լուծումներ վեր հանված խնդիրների վերաբերյալ: Ձեր կողմից տրամադրված ինֆորմացիան կպահպանվի գաղտնի և կօգտագործվի միայն հետազոտական նպատակներով: Ձեր անունը կամ այլ տվյալներ գրված չեն լինի զեկույցի մեջ, միայն որոշ մեջբերումներ կներկայացվեն վերջնական զեկույցում, սակայն դրանք չեն նշելու Ձեր անունը կամ որևէ այլ տվյալ Ձեր անձի վերաբերյալ:

Հետազոտության ընթացքում նախատեսվում է իրականացնել 15-20 հարցազրույց՝ մանկական քաղցկեը բուժող բժիշկների հետ: Եթե համաձայն եք, ես կձայնագրեմ մեր հարցազրույցը, որպեսզի բաց չթողնեմ որևէ կարևոր ինֆորմացիա: Եթե Դուք չցանկանաք, որ մեր զրույցը ձայնագրվի, Ձեր իրավունքն է հետազոտության ընթացքում ցանկացած պահի խնդրել անջատել ձայնագրիչը: Այս հետազոտության վերաբերյալ ցանկացած հարց ունենալու դեպքում, Դուք կարող եք հարցնել ինձ կամ կապ հաստատել Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության ֆակուլտետի դեկան և հետազոտության հիմնական հետազոտող՝ Վարդուհի Պետրոսյանի հետ, հետևյալ հեռախոսահամարով՝ (060) 61 25 92: Եթե Դուք կարծում եք, որ Ձեզ որևէ կերպ վնասել կամ Ձեզ հետ ճիշտ չեն վարվել հարցազրույցի ընթացքում, Դուք կարող եք դիմել էթիկայի հանձնաժողովի համակարգող՝ Վարդուհի Հայրումյանին տվյալ հեռապխոսահամարով՝ (060) 61 26 17: Եթե համաձայն եք մասնակցել, կարո՞ղ ենք շարունակել: Դուք համաձա՞յն եք, որ ես միացնեմ ձայնագրիչը: