

**Understanding the Barriers to Chemotherapy Treatment in Breast
Cancer Patients in Armenia: a Qualitative Study**

Master of Public Health Integrating Experience Project

Professional Publication Framework

by

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ACRONYMS AND ABBREVIATIONS

BBP	Basic Benefit Package
BC	Breast cancer
BCP	Breast cancer patient
FM	Family members
HCP	Health care provider
LMC	Lower-middle Income Country
MOH	Ministry of Health
NCD	Non-communicable disease
NOI	National Oncology Institute
RA	Republic of Armenia
WHO	World Health Organization

ABSTRACT

Breast cancer (BC) is the most common type of cancer among women worldwide. It comprised 23% of all new cancer cases and 14% of all cancer deaths worldwide in 2008. The recent increase in morbidity and mortality rates of breast cancer is a great area of concern in lower-middle income countries, where the survival rates are low due to lack of awareness about the disease, late diagnoses, and lack of resources and appropriate health care infrastructure.

Non-communicable diseases (NCD) contribute to 90% of all deaths in Armenia; 16% of all deaths are caused by cancer. There is no nationwide statistics on the BC rates in Armenia. According to unpublished data obtained from the Statistical Department of the National Oncology Institute after S. Fanarjyan, the incidence rate for BC in 2012 was 66.5 per 100,000, and the mortality rate was 37.4 in the same year. There are no published articles or reports about the current situation with access to and quality of breast cancer care in Armenia. The aim of the current study was to examine the process of delivery of chemotherapy and the barriers to receiving chemotherapy in BC patients, explore the cost and quality of chemotherapy drugs currently used for treating BC patients, and come up with some recommendations about how to improve chemotherapy services in Armenia.

The student investigator conducted twenty two in-depth interviews among BC patients who received chemotherapy in the last 5 years, family members of BC patients, and healthcare providers, including oncologists and chemotherapists, using a semi-structured interview guide. The interviews were conducted in the capital Yerevan. Directed content analysis was used to analyze the data.

The study identified several important barriers to chemotherapy in Armenia, including high cost of chemotherapy drugs paid for by patients out of pocket, queues at health care facilities, obsolete and unevenly dispersed infrastructure, outdated equipment, and lack of awareness about BC in general, screening for BC, and BC care in general population and BC patients. The study revealed that lack of professional training opportunities for healthcare providers hinders the delivery of high-quality care and leads to dissatisfaction with services among providers and patients. Poor provider-patient interaction in some of the healthcare facilities providing chemotherapy services to BC patients may further complicate the treatment process and worsen treatment outcomes.

The numerous barriers to high-quality cancer care for BC patients could be at least partially overcome with the development and implementation of the national strategy on BC that would minimize the financial burden of treatment on the population and increase geographical access to care for the patients in regions, and the technical and organizational upgrade of the largest public cancer hospital in the country.

INTRODUCTION

Breast Cancer

Breast cancer (BC) is a type of cancer that occurs in breast tissues, particularly in the ducts (tubes that carry milk to the nipples) and lobules (glands that are responsible for making the milk).¹ It is the most common type of cancer among women worldwide. ¹It comprised 23% (1.38 million) of all new cancer cases and 14% (458,400) of all cancer deaths worldwide in 2008.² About 50% of all BC cases and 60% of all deaths occurred in economically developing countries.²

The main risk factors for developing BC include older age, family history of BC, early age menstruation (below 12 years), exposure of the breast to ionizing radiation, giving first birth at older age, not giving birth during lifetime, the usage of hormone replacement therapy (usage of estrogen and progesterone for menopause), obesity, the alcohol use, use of oral contraceptives, not getting regular exercise, not breastfeeding, and being white.^{3- 11}

Access to Quality Breast Cancer Care in Countries with Limited Resources

There has been a notable decrease in BC mortality rates in North America and Europe over the past 25 years, mostly attributed to extensive screening programs, early detection and improved adjuvant systematic treatment.^{2,7,12,13} For example, in US, since 1989 there has been a constant decrease in BC mortality rate for 2% every year, with a cumulative 6.8% decrease achieved by the year 1993.

The outcomes are less positive in the developing world. The percent of deaths among all incident cases was 24% in high-income countries in 2008, compared to 48% in low-income, 40% in lower-middle-income, and 38% in higher-middle-income countries.¹² The high

probability of dying from breast cancer in the less developed countries reflects poorer early detection and access to treatment.¹² For example, while mammography screening is recommended as an early detection tool for the countries with well-developed health infrastructure, it can be overly expensive and inaccessible to women in the low-resource environments, resulting in the diagnoses at later stages.^{9,14,15} In the majority of lower-middle-income countries nearly 50-80% of women diagnosed with breast cancer have it at the late stages such as the advanced stage III or metastatic cancer Stage IV.¹⁴ In India, the BC in late stages is diagnosed in 50% to 70% of patients, while in US only 30% of patients are diagnosed in late stages.⁹

The absence of adequate healthcare infrastructure and resources in lower income countries, besides leading to later diagnosis, results in poorer quality of treatment in those already diagnosed.^{14,16} The access to quality cancer treatment is the area of greatest concern in these countries.^{9,17} For example, in order to have a systematic chemotherapy available for BC patients, the countries should assure the availability of drugs as well as appropriate infrastructure and well trained staff in health care facilities,⁹ which is hard to achieve with the chronic lack of resources experienced in these countries. The continuing escalation of the chemotherapy costs is a concern for healthcare providers and patients throughout the world.^{18,19} In less developed countries these costs are covered out of pocket imposing heavy financial burden on patients, and leading to irregular or delayed treatment.¹⁷ However, for the chemotherapy treatment to be effective it is crucial to administer it according to the assigned schedule.¹⁷

In addition to unaffordability of the treatment, geographical access may present another challenge for getting the timely treatment in less developed countries.²⁰ Due to the lack of appropriate facilities in regions, patients may have to travel for dozens of kilometers from

regions to big cities or capitals to get the treatment, and it might create additional financial and logistical difficulties for the patients.²⁰

Another determinant of poorer BC outcomes in lower income countries is the low level of awareness and misconceptions about the BC treatment that can complicate the treatment process²¹ and make women with BC to look for non-standard types of treatment or alternative medicine,^{9,22,23} which have been validly criticized by the providers of conventional medicine.²⁴

In limited-resource countries it is harder to recruit, train, and retain healthcare professionals.²⁵ In such health care systems it is often impossible to provide competitive salaries for well-trained health personnel in cancer care,⁹ which might lead to frustration with the system among providers, lower the quality of services. and serve as another barrier to receiving quality cancer care by the patients.

The absence of adequate cancer registries which could support the countrywide or regional research on BC with the aim of accurately describing the situation with BC and informing evidence-based decision making, is yet another important challenge for countries with limited resources.^{10,16,20}

Situation in Armenia

The Republic of Armenia is a lower-middle income country located in the Southern Caucasus with the population of 3,262,600.^{26,27} Armenia has 11 administrative/geographical districts (marzes), including the capital Yerevan which is the largest urban center where roughly half of the population reside.²⁸ The country's health care system underwent substantial changes after the collapse of Soviet Union, switching from the highly centralized Semashko model to

largely fragmented decentralised system, predominantly financed out of pocket. ^{11,26,29}

Decentralization also led to the shift in the responsibility for service provision from central to local health authorities and the privatization of a large number of health care facilities. ^{11,26}

The hospitals are generally multi or single profile hospitals and the outpatient care is provided via polyclinics. ²⁶ In 2008, there were 27 private hospitals and 94 public hospitals controlled by the Ministry of Health of the Republic of Armenia. ³⁰ The National Oncology Center after S. Fanarjyan (NOI), which is the largest public oncology center in the country is located in the capital Yerevan and provides diagnostic services, surgery, and chemotherapy treatment to cancer patients. The private hospitals that provide cancer care include Shengavit Medical Center, ArtMed Medical Center, Nairi Medical Center, and Surb Grigor Lusavorich Medical Center.

According to WHO, in 2010 the non-communicable diseases (NCDs) comprised 90% of all deaths in Armenia. ³¹ Sixteen percent of all deaths were attributable to cancer (all types), 40% to cardiovascular disease, 7% to respiratory disease, 8% to diabetes, 6% to communicable maternal, perinatal and nutritional conditions, 4% to injuries, and 13% to other NCDs. ³¹

Currently there is no national cancer registry in Armenia, and no data on the current national distribution of the morbidity and mortality according to different types of cancer and/or socio-demographic strata is publicly available from the National Statistical Services of Armenia or MOH. According to GLOBOCAN 2008, the age standardised incidence rate for BC among women was the highest among all cancer types in Armenia: the incidence in 2008 was nearly 29% of all cancer types (1,065 women), and the death comprised for 20.1% among all cancer types or 601 women. ³² According to the unpublished data provided by the Statistical Department of the NOI which is the largest source of cancer care in the country, the incidence rate for BC in 2012 was 66.5 per 100,000, and the mortality rate was 37.4 in the same year. ³³ However, these rates are only estimates based on the data from National Oncology Institute.

In 2009 the mortality rate from BC in 2004 was 16.4 deaths per 100,000; the incidence rate was 59.6 per 100,000 and the BC was considered to be the eighth leading cause of death in Armenia in 2006.³⁴

As in many LMCs, in the majority of cases the health expenses of BC patients in Armenia are largely covered out-of-pocket.⁹ Although the MOH introduced a number of regulations since independence (1991), to support the treatment of BC patients, the situation in the regulatory field has not been stable. For example, in 2006, the law N 1717 was introduced by the Government which stated that all cancer patients should get tumor medication and painkiller drugs free of charge³⁵ However, recently the decision was made to cover treatment expenses of the oncological patients on the copayment basis (Law N299-A accepted on February 7, 2013).³⁶ To our knowledge, none of the introduced schemes were evaluated to see if the suggested payment mechanisms were effective for patients, providers, and the system in general.

There are no published studies or reports or any other types of evidence-based information about the current situation with access to and quality of breast cancer care in Armenia. However, some anecdotal evidence gets published in local media from time to time, uncovering problems which could be the tip of the iceberg in the field of cancer care in the country. Most of such evidence suggests that Armenian women are paying for treatment out of pocket, and few have access to high-quality affordable drugs. For example, in the article posted by “Panarmenian” news web site³⁷ in 2011, it was stated that almost 30% of women with BC are currently prescribed an expensive drug Herceptin, which costs USD 3,000 per ampule. The whole treatment consists of 18 chemotherapy rounds, and the cost for the full treatment totals to USD 54,000, which is much higher than what most of Armenian families can afford.³⁷ The recent article by Arka News Agency included the discussion of the market

of medicines in Armenia, and in particular, the low quality of cancer treatment drugs used in the country.³⁸ The interviewed experts mentioned that the market is poorly regulated by the Government which leads to the situation where anyone can import any type of drug. One of the experts pointed out that “Armenia’s market of medicines is abundant in low-quality cancer drugs”.³⁷ In another article from the same source the authors claimed that cancer drugs are very expensive and not all the patients can afford it, with Armenian doctors having to “both treat cancer and raise funds for the treatment”.³⁷ In the same article it was mentioned that the cost for the newer generation high quality cancer drugs can reach up to USD 10,000USD for a single course of therapy.³⁷ The absence of nationwide statistics and published research in the field of BC treatment in Armenia, and the alarming evidence presented in the media suggest a considerable need for a study that would describe the experiences of Armenian women with the BC treatment currently offered in the country. The aim of this particular study was to identify the major barriers to chemotherapy treatment in Armenian women with BC and suggest the possible ways for improvement based on the analysis of information and recommendations provided by the BC patients themselves, family members of BC patients, and health care providers working with BC patients.

Research Questions/Study objectives

The study aimed to answer the following research questions:

- How is chemotherapy arranged for women with BC in Armenia?
- What kinds of barriers to chemotherapy do women with BC face today?
- What are the different types and ranges of chemotherapy costs for women with BC in Armenia?
- What are the possible ways to improve the access to and delivery of chemotherapy for BC women in Armenia?

METHODS

Study design and participants

The study utilized qualitative research methods including in-depth interviews (IDI) with different respondent groups. Purposive and snowball sampling techniques were used to recruit participants. The participants were recruited through personal connections and health care providers. The respondents included BC patients who have received a chemotherapy during the last 5 years or were in the process of receiving it at the time of the study; health care providers that directly work with breast cancer patients (oncologists and chemotherapists), and family members who have taken care of BC patients in the past or were taking care of BC patients at the time of the study.

Since in Armenia BC patients are often not aware of their diagnosis, health care providers and/or family members of BC patients were contacted first. After getting their permission and learning about whether the patient is informed about the diagnosis, the interviewer arranged the interview with BC patient.

Instrument

In-depth interviews were conducted using three semi-structured interview guides (Appendices 1-6) which consisted of open-ended questions. The instrument was developed by the student researcher based on the literature on access to quality cancer care. The questions were grouped into following domains.

1. The timeline of the treatment
2. Access to chemotherapy
3. Financial burden of chemotherapy treatment
4. The satisfaction with the received treatment
5. Suggestions for improving the current access to and delivery of chemotherapy for

BC women in Armenia

The guides slightly differed in content for different groups of participants based on the specific research focus set for a particular group. The first IDI was used as a pre-test to detect the inappropriate questions in the guide and the study protocol. The guide and the consent form were slightly revised for the subsequent interviews.

Data Analysis

All interview records and notes have been transcribed and translated from Armenian to English. Data analysis included the ongoing review of the transcripts and identification of the common patterns. The data collection was stopped after the saturation was achieved. The data were coded and categorized according to the following predefined themes: 1) arrangement of chemotherapy in Armenia, 2) existing barriers to chemotherapy for breast cancer patients, 3) overall treatment and chemotherapy costs, 4) recommendations and suggestions from participants. Other themes that emerged during the analysis were carefully reviewed and analyzed, and labeled as provider-patient interaction and the professional training opportunities for HCPs.

The interviews of health care providers, family members and breast cancer patients were analyzed separately; after the separate data analysis the findings from 3 groups were triangulated. In order to keep the confidentiality and anonymity, and make the triangulation visible to the reader the quotes were coded in numerical order in each box and presented in the results section.

Student investigator conducted the data collection, transcribing, and data analysis.

Study setting

The interviews from HCPs were conducted in 5 different health care facilities that provide chemotherapy and surgery to cancer patient, including one public and four private facilities. Most of the family members preferred to have the interview in their work places and public parks. The patients who had jobs, also preferred to have the interviews at work, because they did not want their relatives to be present during the conversation.

In general, HCPs were more willing to participate in the study than BC patients and family members. However, most of them were hesitant to talk about problems with the distribution of free drugs or about the quality of services provided in the public hospital. The interviews with family members and patients did not have fixed setting and the place and time was chosen by the participant. Some of the FMs and BCPs did not want to discuss the details of the treatment, and were getting emotional so the interviewer had to use different interviewing techniques to obtain more information.

Ethical Considerations

The study was approved by the Institutional Review Board (IRB) of the American University of Armenia (Appendix 7). Appropriate measures were taken to ensure that the study does not harm neither the patients/family members nor health service providers. Anonymity of study participants was assured. The quotes from individual participants included in this report were de-identified. Oral consent (Appendices 8-11) was obtained from health care providers, BC patients, and family members of the BC patients.

RESULTS

Administrative results and demographic characteristics of participants

Overall, 25 in-depth interviews were carried out. The duration of interviews ranged from 20 to 90 minutes. Seven of the interviews were conducted with health care providers, 11 with breast cancer patients, and seven with family members of breast cancer patients. There were 4 refusals in the study. The reasons for refusal included reluctance to talk about the sensitive topic and not being able to arrange the interview. The health care providers that participated in the study were employed by both public and private hospitals and included four oncologists and three chemotherapists.

The majority of the BC patients had received the chemotherapy in the National Oncology Institute after S. Fanarjyan and later underwent the surgery on the breast tissue. Two breast cancer patients were from marzes. Three of the patients have received the chemotherapy after the copayment law was introduced in January 2013, with one of them receiving the treatment both before and after the admission of the law. Two of the patients continued their treatment abroad (Germany), after receiving 1 or 2 shots of chemo in Armenia. Six out of 11 interviewed patients were married. The average monthly expenses of the patients ranged from 101,000 to 200,000 AMD (USD 246 to USD 487). Three of the family members who participated in the study have lost their relative due to breast cancer.

Arrangement of the chemotherapy for BC patients in Armenia

All respondent groups were asked about how women get diagnosed and referred to chemotherapy treatment and how the chemotherapy process is arranged. All participants mentioned that most women go for screening in the late stages. All patients who participated in the study have gone through screening after having pain or feeling a tangible tumor near the breast area. Almost half of the patients who participated in the study have passed the

screening in NOI and the other half in Mammography Center. Some complained about the manner in which Mammography center communicated their diagnosis.

Also, there were women who learned about their diagnosis after having received their 1st chemo.

“Our mentality is very wrong, we do not go to a physician or screening until we have something really serious” *FMI*

“I went to mammography screening at Mammography center on Heratsi Street. There they told me that they do not see anything good and that I should promptly have a surgery in 12 months period. I did not like that they were saying it so directly, I think they could say it in milder way, because I was really shocked by the diagnosis.” *BCPI*

“...the earlier they are diagnosed the higher is the probability of getting cured..... People do not have that much money to pay for the screening and I would say that there are also people who do not know about such disease or screening.” *HCPI*

Most of the women made a decision about where to go for the treatment based on the advice or recommendations from their relatives, friends and neighbors. Some of the patients had the chemotherapy before the surgery, while others received it afterwards. To receive the chemotherapy treatment the patients had to register at the healthcare facility, which some described as a time consuming and complicated process.

“I was diagnosed and registered in NOI, overall the quality of treatment was good, but the paperwork was very stressing, you should stay for hours to get a single paper or pass some, examinations, sometimes I came there for 2 days for

only the paperwork.”

BCP1

“ ... the registration process was really awful: long queues, no conditions, always run after this or that paper... I do not know even which one to mention..”

FM1

“...the whole process for getting the treatment, being registered was unexplainably bad. My sister has to wait for 4 or 5 hours to be registered. And the most sad thing is that after each chemotherapy the patient was discharged from the hospital, and 3 weeks after she should return and wait for 4-5 hours again to be registered for chemotherapy, the queues were terrible, and everywhere. Queues for being registered, queues for receiving chemotherapy, queues for entering the oncologist’s cabinet etc...”

FM2

When asked about the time period and phases of the treatment all participants mentioned a similar timeline. On average the chemotherapy courses require 4 to 8 shots, the interval between the 2 courses of chemotherapy is 21 days or 3 weeks.

“In case of BC, according to the scheme it is 4-8 rounds. The chemotherapy is done once in 21 days interval. We try not to delay the treatment for patients to have good outcomes, in our department we manage to apply this approach. The average maximum time for completing chemotherapy is 160 days. The average minimal time for chemo is 80 days including 3 weeks intervals.”

HCP1

“If I am not mistaken, on average one treatment of chemotherapy through IV injection, lasted for 3 or 4 hours, with 3 weeks of interval. I received one

chemo before the surgery in Yerevan, and another two after the surgery in Germany.”

BCPI

Most of the providers mentioned that they prescribe chemotherapy treatment according to the protocols they use. One health care provider mentioned that Armenia does not have any officially accepted protocols; that is why they use international ones, and the very first time they learned about those protocols was during their residency at Yerevan State Medical University (YSMU). Most of the health care providers could not name any protocols; saying that they either forgot the name or that there is no specific name for the protocol. Only one health care provider from NOI mentioned names of the 3 protocols used for breast cancer treatment (Sungale, NCCN and ESMO). The same health care provider mentioned that these protocols change based on updates that come from oncologists worldwide, and some of our oncologists also take part in the updates of certain guidelines, because some of their colleagues are members of the team from ESMO that works on protocol updates. Many of the health care providers also mentioned that the treatment differs according to the tumor type. However, due to lack of resources some HCPs have problems with the full adherence to the protocols.

“The chemotherapy is arranged as it is arranged in all other hospitals of the world, it is organized and planned in a very appropriate manner, with some general standards it should adhere to. It is based on personalized approach. And in our hospital it is not an exceptional thing. There are protocols about how it should be arranged”

HCP1

“Armenia does not have any accepted protocols yet. I think that if a country does not have its accepted protocols, it cannot require from the doctors to apply the protocols for the treatment. But in some cases, the oncologists and chemotherapists have some internal agreement, and based on this agreement we choose internationally accepted protocols and move forward, make decisions on treatment based on those protocols... There are three main protocols one is NCCN-American protocol, ESMO- European protocol and Sungale, which is number one for me, and offers the treatments for early stage BCs.”

HCP2

“...working with original protocols is very difficult, as we do not have all required resources both material and technical for organizing appropriate examination. That is why we try to work according to what we have”

HCP3

Barriers to chemotherapy in breast cancer patients

1. Lack of awareness

Though all health care providers mentioned overall increase in the awareness level of the population about BC and BC treatment in the recent years, they thought it is still low and is a barrier to treatment. As most of the health care providers and patients mentioned, the more the patients know about the disease, the better providers and patients understand each other thus making the treatment process easier.

“What concerns the awareness level, generally, we tell the patients about the disease, that it is a malignant neoplasm; it is quite difficult to tell such information to the patients in Armenian context, because our population is quite uneducated on the issue.”

HCP1

Some information through media or other venues, describing where to go for screening, when to go, what chemo is, why it is provided, how long does it take, that the hair loss is recoverable... There are small questions, that interest them, and when they understand, all that fear will be gone. Currently the patient does not possess any of this information. “

HCP2

“... there is a huge shortage of correct medical information delivery. The patient knows that there is something with the tissue, but does not possess any correct information; so if they knew that there should be puncturing then surgery, then the price is this much, the effectiveness of treatment this much, and have the right impression, it is more likely that they would approach the specialists.... If they know the right chain of treatment, the number of patients would also rise”

HCP3

“There is slight increase in the level of awareness, but this is only real for Yerevan, in marzes, of course not in all marzes, the situation is terrible, many people do not know what cancer is. Our population needs to be educated not only on the issue of cancer but in general there is need of medical knowledge among general population, starting from the hygiene and finishing by the Alzheimer’s disease”.

HCP4

Nearly all health care providers mentioned that they themselves try to provide as much information to the patients as possible, but much depends on the patients. If a patient wants to know the details about the disease and the treatment, the health care providers deliver that information, but if the patient does not want to, they do not touch upon that topic.

“The education or knowledge that patients generally have, is provided by us, but it depends on the demand from the patients.... It is very individual and cannot include more than one patient..... Whoever requires the explanations receives them, but those who do not want to, we must not tell them, because it can lead to not desirable psychological outcomes. It can be stressful.” *HCP1*

Most of the providers mentioned that the information about BC is delivered after the diagnosis, when women first go to the surgeons or oncologists and chemotherapists. In the public hospital, the provider told about an educational program for BC patients organized by their chief of the department out of pocket. The program was mainly about the treatment of the disease in general, and included some additional information about pre/post-surgical care. One of the providers mentioned that people have different responsibilities and everybody should do what he is supposed to do, and that it is the responsibility of the Ministry of Education to provide information to the population before people get sick.

“Some time before this, our chief of the department has organized some educational program with Roche company ...(they developed) brochures for BC patients, which were actively distributed among patients in the hospital. Those brochures were written in a very understandable language, so that everyone could understand what it is about.” *HCP1*

“...there are no “official” educational programs.... The educational programs should not be provided only to those who already have the disease, it should be done much earlier to avoid the rates that we have now. So it is the ministry of education and ministry of health that should think about how to educate people, I am not a teacher to educate, I am a doctor, I provide treatment, the way I will tell people about the disease will differ from the way

2. Queues in health care facilities

Another barrier identified by the participants was the long queues, mostly in the public hospital, both for the registration and for receiving the chemotherapy. Almost all participants except the health care providers that worked in private clinics admitted the existence of queues in their health care facilities, however, some refused to go into details about the reasons of having queues saying that it is more of a political issue and does not concern our study purpose mentioned in the consent form. One of the health care providers tried to explain the queues in the hospital, saying that the queues are a result of poor financing of health care facilities. The public hospital received funds every month, and every month there is a fixed number of patients that can be served. However, the number of patients is much higher, and it leads to queues. According to participants, the queues substantially influence the treatment outcomes, because there are patients who cannot receive the chemotherapy on time thus reducing the effectiveness of the treatment. Some of the oncologists mentioned that the delay of the treatment even for 2 days can influence the effectiveness of the chemotherapy.

The private clinics manage to serve all their patients on time, thus not jeopardizing the effectiveness of treatment. The reasons for being able to serve the patients included higher prices in private clinics. Since few patients can afford such treatment, the private clinics do not get overloaded, while the public clinics do not manage to serve all their patients because they have too many.

“...the queues were terrible, and everywhere. Queues for being registered, queues for receiving chemotherapy, queues for entering the oncologist’s cabinet, etc.”

FMI

“Why are there queues? Because there are no sufficient finances to provide care to all the patients on time. But let’s not go into details. The queue is a problem. But I will not talk about the causes. It is already a political question. If there was an increase in financing, the queues would disappear. Everything depends on the finances.”

HCP1

“It is very difficult for us to work with these queues, the labs do not manage to do their work on time. The queues are not artificially created, it takes a lot of time for the patients to get registered and to reach us, both from the point of view of the location of health care facility and registering process, people have to wait for hours, days to have their papers admitted...”

HCP2

“there are many reasons for queues; as our clinic receives a certain amount of money for a certain number of patients for a one month period, when we spend the money (governmental money) we do not have place anymore to admit other patients, so there are no real queues but in this case there are virtual queues, because we have already spent all financial resources that the hospital received for that month”

HCP3

Some of the participants mentioned that after the copayment law the queues slightly decreased. The participants reported that before patients had to register several times for each shot of chemo, while currently patients do not have to register several times. Another participants thought that there are fewer queues now because fewer people get registered after the co-payment scheme went into force.

“ well, yes there are queues but not very long, as far as I heard people said

that they waited for days, I have waited for 4 hours...Queues decreased, I think because not that many people come to be registered...before the idea of free treatment made people come, currently knowing that everything should be paid out of pocket frightens people....”

BCPI

3. Lack of equipment and supplies

Other barrier to treatment that was discussed by the majority of participants was the lack of appropriate supplies and equipment to provide care to the patients. Some of the health care providers mentioned that the outcome is highly dependent on the necessary resources such as technical resources, disposables that are spent every day, etc. According to the health care providers, without having all resources no one can guarantee the effectiveness of the treatment and good outcomes.

Most of the participants explained the lack of resources by the lack of investments in the sphere. The highest need for resources is in the public hospital. The health care providers from the public hospital mentioned that the equipment is very old, they do not possess appropriate diagnostic equipment and cannot offer appropriate conditions for patients, while in the private hospitals the situation with equipment was relatively better.

“The process of delivering the chemo is not done with high quality. Today there are many new approaches that are widely applied abroad, but can not be used here, for example the infusion ports; it is a new system allowing to make the chemo injection from central venous. Abroad once a patient is operated just after that the port is installed. Here such port costs 300,000-400,000 AMD “

HCP1

Provide appropriate technology. We do not have any financial resources

to make the hospital technically equipped, which would improve the survival. The hospital does not have any new equipment. The diagnostic equipment is 40 years old, if not older.”

HCP2

All participants, particularly FMs and BCPs talked about poor conditions in the health care facility. Even when asked about other aspects of care they kept talking about bad conditions, dirt, and old equipment in the health care facility.

“The conditions were awful. Starting from the (doctors’) cabinets. The cabinets were very small. Some did not even have the examination table.

In general the clinic was very poor.”

FMI

“When you enter the hospital, just from the beginning you feel bad, it’s a messy hospital, it does not provide any sense of calmness, at least it would be better to see it clean, all those issues have impact on people’s mental health”

BCP1

“.. the department was in such a situation that my mother even said “Probably this department is for those who do not have any hope to survive”

FM2

“As far as I remember, in the whole department there was one hospital attendant, and many patients, what care you would expect in such conditions? I do not know whether you had seen their patient beds, it is like you feel you are in barrack. I do not speak about dirty linen there.”

FM3

4. Distance and transportation

The issue of the transportation costs was raised by one of the health care providers in NOI and one of the patients that had to come from marz to Yerevan to receive the treatment. The participants mentioned that there are people who cannot pay for transportation, and they might miss the treatment or delay it as a result.

“ I come to NOI from Qajaran once a month for getting the treatment... it is already the 3rd time I came here and I can say that I have spent more money on the transportation than on the treatment.”

BCP1

“If you ask people coming from marzes they will tell you that they do not have even money to reach the hospital. Everything depends on finances. There are people who do not even have money for transportation. They cannot get the treatment on time, or in case if they get it, it is on late stages.”

HCP2

“...we do not have car, of course it is very expensive to come from Artik to Yerevan. It is even expensive for my relatives, as they come to see me, and they spend money for coming, for bringing me food, for helping to buy some additional drugs. It is rather expensive.”

BCP 3

5. Cost and accessibility of drugs in Armenia

The majority of participants mentioned the treatment price as the number one barrier to treatment. According to participants, the majority of the patients cannot afford appropriate treatment because of the lack of appropriate financial support from the government, and low social-economic status of the population. Some patients interrupt the treatment because they cannot afford it. The patients who received the treatment under the law on free drugs for cancer patients, paid out of pocket despite the law.

“Number one problem for treatment is the price. Modern treatment is very expensive.” *HCP1*

“Too much uncertainty on the outcome of the treatment is present during the whole treatment process and you do not even know whether after receiving those expensive drugs your relative will become healthy again. “ *FM1*

“It is very hard for the family to know that you cannot help because of the absence of money” *FM2*

“ If the problem could be solved by the government and people could afford the medications it would not be so terrible as it is now. Taking into account the fact that among most cancers breast cancer is the most treatable, but in our country many patients die because the treatment is too expensive, it is really very very sad and you do not know whether something will ever change.” *HCP2*

Most of the participants mentioned that the price for chemotherapy varied according to the drug and treatment scheme. Most of the patients reported that they have paid a certain amount of money for chemotherapy, and for each patient the price was different, from 15,000AMD (USD...) to 1,000,000AMD (USD...) and more. For example concerning the Herceptin, some mentioned that only an ampoule cost USD 30005000 (AMD 1,230,000-2,050,000).

“I pay 110,000 AMD for each chemo shot plus some supplementary drugs, which are also rather expensive and my salary is 240,000 AMD, how do you think I live? If my relatives did not help me, I would never be able to

<i>receive appropriate treatment...”</i>	<i>BCP1</i>
<i>“Overall we paid nearly \$12,000 in one year for the treatment, for the surgery, the screenings and a number of tests but she received the best care, I think. The drugs were very costly. Even once we were talking, and she said, if we were living like average citizen, I might have not survived.”</i>	<i>FM1</i>
<i>“Concerning the access, the drugs were very accessible but not for everyone. The prices for chemo drugs start from minimum of 11,000 AMD and reach 300,000 AMD and more, the doctor even said that there are even more expensive drugs, for \$10,000, but if a person would have that much money for a drug, she would rather go for treatment abroad.”</i>	<i>FM2</i>
<i>“The costs start from 200\$, this is the minimum cost for chemotherapy. The price can rise to \$3,000 or \$5,000 for Heceptin for example which is a targeted therapy; and even more for each shot of chemotherapy.”</i>	<i>HCP1</i>
<i>“ On average from \$500-1,000 for one shot of chemo.”</i>	<i>BCP2</i>
<i>“....As it should be used for a long time and if I am not mistaken each ampoule of Herceptin is 3000 dollars, if I am not mistaken.”</i>	<i>FM3</i>

Though all the patients who received the treatment before the law on co-payment was enacted were aware of free drugs, very few of them had the opportunity to get them for free. Two family members stated that they received drugs for free only on the paper. After signing the

document that they received it for free, they paid certain amount of money to the curing doctor.

“ the payments were made directly to oncologist or nurses for the injection of the necessary drugs, if I am not mistaken every injection was nearly 20,000AMD”

FM1

“...These free drugs are free only on the paper. My sister was signing a paper telling that she received the drugs for free, but in reality she paid to curing doctor to get the drugs.”

FM2

Another concern mentioned by the patients and family members was the quality of drugs. Some of the patients did not get free drugs because they thought they are not effective. Healthcare providers were somewhat hesitant to discuss the quality of free drugs. Some of them mentioned that there is supply of all drugs; however, much depends on the patient, whether the family can afford a certain drug or not.

“ I do not know how they function, those free drugs, but I am sure they are not that effective. I did not apply for these free drugs.”

BCPI

“...at that time in 2009 the (chemotherapy) drugs were included in the basic benefit package, and all of them were old chemotherapeutic drugs, very old ones; in modern literature those drugs are contraindicated as they have many bad side effects.”

FM1

“It is not that we do not know about the existence of other drugs, of course we know, and believe me everything could be done in Armenia if the patient has enough money to buy the best drug, which is very expensive. Both the

<i>educated specialists and technology are available to provide the treatment, but the financial status of our population is very low... “</i>	<i>HCP1</i>
<i>“Concerning the quality, a high quality drug is very expensive. If it is a high quality drug of a certain brand, or a very new drug it would be very expensive”</i>	<i>HCP2</i>
<i>“My drugs were sent from abroad, because I did not know whether the drugs supplied in Armenia are original ones or not, whether they are old or not. Many people around me also said that the majority of the drugs are fake. That was another reason why I had some suspicions concerning the drugs “</i>	<i>BCP2</i>

All participants mentioned that the treatment is very expensive and that the new law makes it even less accessible for larger number of patients. According to the participants before the admission of the last law on copayments, the free drugs were received based on the prescription done by the curing doctor in NOI, from the non-commercial pharmacy located in the same building. With the new law, the curing doctor introduces the services that could be covered within 30,000 AMD and the patient chooses any service. They also mentioned that this 30,000 AMD can be subtracted from the overall cost of treatment, be it a chemotherapy or a surgery.

The participants that received treatment after the new law was enacted reported the price range paid for chemotherapy similar to the price range mentioned by the participants that received it before the law. However, all patients that received treatment after the copayment law stated that because many people now know that the treatment is not free, they will not

even go for screening, and the number of patients will decrease in the nearest future, and this will not mean that there are fewer cases of BC; simply fewer people will seek care.

“ ...currently when the support switched to copayment, the chemotherapeutic drugs are mentioned in the list, so the patients know what drug she is prescribed and based on her choice she buys the drugs with some discount from the hospital, other drugs are provided for free before and after the operation” *HCP1*

“ The price that I pay for each shot of chemo is 75,000 AMD, of course my relatives help me, but anyway for 30,000 I buy my monthly rehabilitation drugs, the amount that the government provides is even funny...” *BCP1*

“ ...there was a woman who said that she knew the treatment was free and that served as a reason for coming to hospital. Now when all the services are on her expenses and only 30,000AMD are subtracted, she refused the treatment” *BCP2*

“ It is all about the money. Though there were expenses before as well, but there was some free treatment for many patients, currently if you have BC you are doomed...” *BCP3*

Health care providers’ attitude towards the patients.

The poor provider-patient interaction was one of the important findings that emerged during the analysis. Many patients and family members mentioned about rude and impolite behavior of the staff in the health care facilities, irrespectively of whether it was a public or a private hospital Their reports were in contrast to what providers said. Most of the providers

mentioned that the interactions between them and patients were very good. Some of the patients and family members stressed that chemotherapists and nurses in particular were very rude to the patients. Some mentioned that the staff behaved like patients owed them something, some talked to them in an unacceptable manner.

<p><i>“And the physician was very bad and rude ...and famous for doing illegal jobs with her health care workers and she took approximately 15,000AMD for a single injection from us..”</i></p>	<p><i>FMI</i></p>
<p><i>“.... They behave as if I owe them something. And in my case when the payment was made, and I paid a lot, they could have behaved more politely taking into account at least the fact of payments.”</i></p>	<p><i>BCP1</i></p>
<p><i>“ The nurse was even younger than my daughter and she talked to me like I was her child and she was bringing me up... I do not know what else to say after that...”</i></p>	<p><i>BCP2</i></p>

Lack of professional training opportunities for health care providers

Two family members, one patient and one health care provider mentioned the need for additional education for healthcare providers. In their opinion, the main gaps in the providers' training were in the areas of provider-patient communication, recent developments in the BC treatment, and use of modern equipment.

<p><i>“ We have some problems with the staff as well, especially now when the new generation of doctors is a real problem both for the patients and for the doctors. There should always be educational programs for updating the knowledge of doctors, the medicine in 21 century develops very fast</i></p>

<i>both the methodologies and the equipment, the modern physician should be aware of the technologies as well as have knowledge on treatment methodology”.</i>	<i>HCP1</i>
<i>“...for improving the care, it would be better to send the staff for training.”</i>	<i>HCP2</i>
<i>“You never know about the competence of the physician, he might be well known, but in case of mistake no one will stand by you. In general, our clinics and our staff needs to be completely retrained.”</i>	<i>BCP1</i>

Recommendations for the improvement

Throughout the interviews most of the participants made some recommendations on how the situation in Armenia could be changed for the better. At the same time there were concerns about the transient nature of any changes. The main common recommendation made by all participants was the increase in financial support both to the patients and health care facilities, and the establishment of appropriate regulatory body, particularly in the public hospital, as this hospital serves the majority of breast and other cancer patients in the country.

<i>“Well we all understand that the situation was not good before, even when some services were fully covered by the government, currently the situation will make chemotherapy inaccessible for most patients, particularly from NOI.”</i>	<i>HCP1</i>
<i>“First, supporting poor patients for getting good drugs for the treatment. Maybe the creation of some fund will help. Like the one we have for children with leukemia.”</i>	<i>BCP1</i>

“The government should dedicate some amount of money to health care facilities providing chemo and apply appropriate regulation for controlling the drug delivery. It is not that they sell it, there is no such thing, they just often do not possess necessary drugs. Only in this case more patients will have access to drugs.”

HCP2

“ the only recommendation would be to increase the support, 30,000AMD is even less than the minimum monthly salary, it’s like making fun of us (patients); I always knew that this country is a mess, but I could not imagine that even the basic humanistic approaches have disappeared from our society..”

BCP2

“.... It is necessary to have appropriate medical institutions, clean, which is one of the important parts of the quality of medical services...so that when a patient goes there, he/she feels good, feel normal.”

BCP3

Another recommendation was to have a reform that would completely change the working style of the facilities. Many of the participants, particularly the patients and family members have recommended opening a new Cancer Center, in a different location.

“well the very first and fundamental problem is finance... I think there should be a reform on these issues. It is really impossible to explain, the whole system should be changed, only a reform and continuous investments will lead to change.”

HCP1

“I think there should be completely new center established for cancer

patients: renovating and enriching the current center will cost much more to the country, than building another hospital from zero. “

BCP1

“ what I would suggest is to ruin the current oncology center and build a new hospital, because there is no quality there at all, and even if you receive the care that has some quality, it is based on several individuals who can provide qualified services, in our case it was the curing doctor”

FMI

“ in my opinion it would be better to return to Soviet times, when health care providers were going to regions, examining and treating the patients, this was good both for our population and health care providers as well. “

BCP2

Some of the participants reported the need for larger insurance coverage though they had some doubts concerning whether the insurance companies will cover the oncologic patients.

None of the breast cancer participants had medical insurance; however, the health care providers gave some examples of cases when people had insurance, but the insurance company covered only the surgery.

One of the suggestions was to have a mandatory insurance that would appropriately cover the cancer patients.

” Today we have insurance that covers the operation but does not cover the chemotherapy. So there should be mandatory insurance on oncology in our country, as it is a disease that often ends with death and those who survive had received rather expensive care”

HCP1

DISCUSSION

This study described the experiences of BC patients with the chemotherapy treatment in Armenia and explored main barriers to quality chemotherapy treatment from the perspectives of patients, their family members, and health care providers. The study revealed many important gaps in the process of delivery of care that are likely to decrease the effectiveness of the treatment and lead to poor patient outcomes.

The study revealed that most of the BC patients in Armenia start their treatment at already late stages because of late detection. All three respondents groups mentioned that women go for screening when they already have some health complaints and feel a tangible tumor in their breasts. The detection at later stages is a major area of concern for both the individual patients and their families and the healthcare system in general; first of all, because it decreases chances for survival, and also because the late stage diagnosis requires more expensive drugs for treatment thus imposing larger financial burden on all stakeholders.¹⁴ The late diagnosis is usually a result of inappropriate breast cancer control at the health care system level, and some socio-cultural barriers among patients, including “denial” and fear of the disease, which might negatively influence their care-seeking behavior.^{18,39,40} Those challenges could be partially addressed by the delivery of educational programs about breast cancer and the benefits of early screening nationwide.³⁹

The breast cancer control includes not only direct investments in the sphere but also available clinical services, prevention, early screenings, treatment and palliative care.³⁹ The establishment of a well-developed infrastructure for breast cancer screening both in Yerevan and in the regions, which would include modern mammography equipment, and provision of free screening for certain age and high-risk groups could substantially increase timely

detection, a goal that was at least partially achieved in many countries with developed healthcare system.^{9,17}

In general, the chemotherapy process is arranged similarly in all health care facilities that provide chemotherapy in Yerevan, in terms of using international protocols for prescribing the treatment in the absence of officially accepted national protocols and any guidelines from the MOH. Two of the three protocols mentioned by the healthcare providers in the study – ESMO and NCCN - are widely used throughout the world.^{41 42} However, some providers reported that they often have to deviate from the protocols, because they do not have the appropriate resources, including expensive drugs, to fully adhere to them. The extent and the consequences of such modifications, as well as the difference between prescribed treatment in different facilities providing chemotherapy in Armenia, is definitely subject of a separate investigation.

The important deficiency in treatment revealed in this study was the queues in the health care facilities, which were most common in the public hospital. All of the respondents mentioned about the existence of queues for receiving the treatment, however the study could not identify the reasons and causes for queues in Armenia. Some of the participants mentioned lack of appropriate financing, poor organization, as well as limited physical capacities of the health care facilities. The queues seemed to be less of a problem after the enactment of the co-payment law; however, according to one of the participants, the likely explanation for that is the overall decrease in the number of participants following the introduction of the law. Lack of appropriate equipment and supplies is yet another barrier for providing quality treatment to breast cancer patients.⁴³ There is a need for up-to-date diagnostic equipment in all facilities in Armenia; however, the problem is particularly severe in the public hospital, where some of the equipment is 40 years old. While the private hospitals do possess some

quality basic equipment, the need to keep up with the dynamic changes in the field of medical technologies is not met there as well. Moreover, although the public hospital is currently the main oncology center of the country serving the largest proportion of BC patients, the basic conditions for patients are absent there. Even the patients' rooms and sanitary facilities are in complete disarray. Even the patients' rooms and sanitary facilities are in complete disarray. Apparently, equipment and material resources are important factors that influence both the processes of delivery of care and the outcome of care.⁴² Yet these factors are also the ones that need the investment of substantial resources which is challenging for a country which had a state health budget of 67, 020, 675,200 AMD (USD) in 2012. ⁴⁴

The need to travel to the capital to get the treatment for those living in distant regions of the country is yet another barrier for getting timely care. The travel is associated with substantial expenses and can be time consuming. People have to travel to Yerevan not only for getting the treatment, but also for screening, since the corresponding infrastructure is virtually non-existent in regions. The situation in Armenia is similar to what was found in other lower-income countries where difficulties with reaching the medical centers are described as one of the most important barriers to treatment.⁴⁵ The lack of appropriate infrastructure hinders the care and might lead to late diagnosis and poorer outcomes among women from regions and particularly from rural areas.⁴⁶

The most important barrier for BC patients in Armenia today is the cost of the treatment. High quality chemotherapy drugs are very expensive in Armenia as anywhere in the world and the drug costs constantly rise.¹⁸ While in some of the countries with more developed health care systems the cost of the drugs is covered by insurance or the government, in Armenia BC patients have to pay for most of the drugs and treatment out of pocket, and the costs are higher than what most of the families can afford.. The high prices for medical

services often influence the care seeking behavior.⁴⁷ Most of the patients who participated in this study received chemotherapy when the law on free care for oncologic patients was still in force; however, apparently the law has never been appropriately implemented.. All patients reported paying for whole or most of the chemotherapy treatment. Some mentioned that they paid for drugs after signing the document that stated that the patient received the drug for free, which was apparent violation of their patient rights. The cost of different chemotherapy drugs start from USD 200 per ampoule and can reach up to USD10,000 per ampoule, and the higher the quality of the drug the higher the price. The expensive drugs are not accessible for the majority of Armenian families. The cost of single chemotherapy shot for BC patients in this study ranged from USD200 -USD 5,000. The changes after the introduction of copayment law were almost negligible; the most important difference being “legalization” of patient payments which were previously paid “under the table”. However, the ones who received the care, after the law was introduced, did not believe in positive change, in contrast most of them strongly believed that it would even worsen the situation with BC care, because with free care, at least some of the patients were able to receive some of the care for free; while with copayment, they get very limited financial support from the government.

The treatment process get further complicated because of the lack of awareness among patients about the disease and the treatment process. While some patients are quite literate about different aspects of care, others have no any information on the topic, thus creating challenges for HCPs to deliver appropriate care in Armenia. Some of the providers stressed that even those patients who have some knowledge on the disease, fear the disease, and do not understand how the treatment should be organized, thus creating the atmosphere of panic around them. Having appropriate and timely information about the disease, the treatment options, and chances for survival can help patients to overcome their fear and be more literate consumers of care delivered by providers, thus increasing its effectiveness.^{48,49} Healthcare

professionals in Armenia should be more engaged in the delivery of appropriate information about the BC and its treatment to BCPs.

One of the most important findings of this study was poor provider-patient interaction at some of the health care facilities, including rude and unfriendly behavior, reported by BC patients and family members. Good provider-patient interaction is very important for reaching better health outcomes; indeed, one of the main barriers to chemotherapy use, particularly for Caucasian women, is considered to be the poor doctor-patient interaction..⁵⁰

In addition, both patients and providers expressed their concerns about lack of professional training opportunities for providers. The knowledge of health care providers is one of the main determinants of high quality care,⁵¹ yet in Armenia the professional development is not supported by the hospitals' administration or the government and is left at the discretion of providers who have to pay out of pocket to participate in international and local training courses. Such environment is not conducive for professional growth.⁴⁰ There is a need for continuous investment in the staff, including refresher trainings and continuous education programs.

STUDY LIMITATIONS AND STRENGTHS

One of the main limitations of the study was the high sensitivity of the topic and the reluctance of some of the BC patients and family members to fully engage in the interviews and talk about important details. Some questions were answered superficially which limited the depth of the information that could be gathered regarding some themes.

Another limitation was the absence of statistical information and the lack of literature published on this topic in Armenia previously, which could guide the development of the study and support its findings. Having more information about the chemotherapy care

provided in Armenia after independence could help to at least track some changes in the process of care delivery and compare the barriers experienced today with those that existed before.

To our knowledge, this is the first study about the barriers to chemotherapy treatment for BCPs in Armenia. The qualitative design helped to collect rich and detailed information on most of the study topics, which would not be achieved had we chosen the quantitative methods to answer the research questions. The triangulation of findings through the inclusion of three categories of respondents added credibility to the study findings. The inclusion of patients who have undergone chemotherapy under different payment schemes introduced by the government allowed making comparisons based on actual patient and provider experiences.

CONCLUSION

This study was the first qualitative study that explored the barriers to chemotherapy among breast cancer patients in Armenia. The most important barriers to appropriate care revealed in this study included lack of awareness on the disease and the treatment processes among patients, long queues in the health care facility, shortage of up to date equipment and supplies, high costs and inaccessibility of drugs for the most of the patients, and poor provider-patient interaction. The largest inadequacies and deficiencies in the delivery of chemotherapy exist in the health care facility that serves the majority of cancer patients in Armenia.

RECOMMENDATIONS

Based on the analysis of study findings, the literature review and taking into account some of the suggestions made by the HCPs, BCPS, and FMs, the following steps are recommended to improve the current situation with chemotherapy treatment for BC patients in Armenia:

1. Development of a multi-component national strategy on breast cancer in Armenia that would focus on the following areas:
 - a. Establishing a nationwide Fund for Breast Cancer Patients that would cover the cost of treatment for all BC patients currently not having health insurance covering BC care and actively fund raising for the fund among local and Diasporan population
 - b. Obliging all health insurance companies currently active in Armenia to cover full costs of BC treatment
 - c. Designing population based educational programs about BC, risk factors for BC, and the benefits of early screening
 - d. Subsidizing free mammography screenings for the women of certain age and risk categories irrespectively of their socio-economic status
 - e. Establishing modern diagnostic and treatment facilities in the regions of Armenia, and until such facilities are established, organizing regular screenings using mobile units in Armenian regions
 - f. Providing support for and control of professional training programs for chemotherapists and other providers involved in BC care.
2. Urgent renovation, equipment, and modernization of the largest public cancer hospital in Armenia
 - a. Involvement of local and Diasporan benefactors in fund-raising and technical support
 - b. Establishment of an independent regulatory body in the hospital which would conduct fiscal and administrative control of the institution and provide regular reports to MOH.

- c. Establishment of the quality improvement committee in the hospital that would explore and monitor the quality through regular patient, caregiver, and provider satisfaction surveys and other means of quality assurance.

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APPENDICES

Appendix 1-English guide for breast cancer patients

Understanding the barrier to chemotherapy treatment in patients having problems with breast tissue

American University of Armenia

Khachatryan Anush

Guide in-depth-interview for patient

ID:

DATE:

PLACE:

Time:

Interviewer:

All those sections will be covered in our questionnaire.

Consent form

As I mentioned in the consent form the aim of my work is to find out what difficulties to patients with breast disorders when getting the treatment.

So I would like to talk to you about the challenges you faced for receiving the treatment and medical care. I have prepared a list of questions that will help to find out the experiences that you have when getting the treatment. Your answers will help us to develop recommendations to improve care for patients with breast problems in the country.

Introduction

To begin our conversation, could you please introduce yourself? How do you feel today? Where are you from? Do you live alone or with your family?

Questionnaire:

General Information on the treatment experience

1. When did you learn that you had the disease? How did you find out that you had the disease? Could you please describe how you were diagnosed with breast disorders, when, where and by whom (probe; physician, radiologist, curing doctor, etc)?
2. Could you please describe your treatment experience step by step? Probe. *In what health care facilities and by what specialist did you receive your treatment?* If you have changed the treatment facility and/or specialist, please explain why? How often do you face any paperwork in the hospital? How often do you usually have to wait for a single round (injection of the treatment) of treatment? Approximately how long do you wait in queue in the health care facility for each treatment? Probe. For hours? Depends on the length of the queue? What would you suggest to improve those processes?

3. Are you receiving treatment now? For how long have you been (did you) receiving that treatment? What is the average duration of the process of receiving the treatment, the frequency of treatment during a year period and the interval between each round of it?

Quality and availability of care

4. What can you say about the overall level of the quality of care delivery that you have received in the health care facility? What do you feel are the best aspects of your care and why do you feel that way? What are the main problems you face in the hospital? What are your suggestions to improve the care?
 - a. Distance – how long does it take you to get to the health care facility for receiving the treatment? Approximately how much money do you spend for getting to the health care? To what extent the distance is a problem for you for getting the treatment? What would you suggest to improve this issue?
 - b. Drug availability – what can you say about the drug availability in the hospital? To what extent are the drugs you need available in the hospital? What happens when drugs are not available?
 - c. Attitude of the doctors – what can you say about the attitude of the doctors, nurses and other staff that provide you with services for breast problems? Overall to what extent are you satisfied with their services? How could they improve the services that they provide?

Cost of Services

5. What can you say concerning the cost of the services for breast disorders that you receive? For what services do you pay? How do you pay for those services? To whom do you pay? Which services are free?

6. To what extent do you receive the drugs that you are prescribed in a timely manner?
What drugs are provided for free and which drugs do you have to pay for? How do you get those drugs? What would you suggest to improve the delivery of the drugs?
7. How would you assess your health after taking the drugs? What change have you experienced? What side effects do you feel after taking the drugs? How do you cope with these effects?
8. How much money have you spent overall on the treatment? Please tell me how you would categorize your expenses and approximately how much you have spent for each category. (*Probes: How much money have you spent on a) transportation, b) drugs, c) diagnostic services d) doctors for treatment e) nurses for treatment, f) cleaning ladies g) any documents (for social support, for disability group) h) other services, if any, please, specify?*) Please tell about the payment process for the treatment in the hospital? Who do you pay to? Please specify for what services do you pay directly to the cashier?
9. Where do you get money from to cover expenses related to your treatment? *Probe. From your family monthly income? Who helps you financially for your treatment? What kind of support has the government provided? What can you tell about the support? How did you get the support from government?*
10. Thank you for your time, is there anything else about your experience as a BC patient that you would like to share?

Now I would like to gather some basic information *about* you and your living *situation*

Demographic Form

ID _____

1.	Are you citizen of Armenia?	1. Yes 2. No if not what country _____
2.	Where do you live?	1. Yerevan 2. Marze → please, specify _____
3.	How old are you?	
4.	What is your marital status?	1. Married 2. Separated/Divorced 3. Widowed 4. Single
5.	Indicate the highest level of education that you have completed:	1. School (less than 10 years) 2. School (10 years) 3. Professional technical education (10-13 years) 4. Institute/University 5. Postgraduate
6.	Are you employed?	1. Yes 2. Yes, but on maternity/pregnancy leave 3. No 4. Self-employed

		<p>5. Seasonal worker or farmer</p> <p>6. Student</p> <p>7. Retired</p> <p>8. Other (<i>specify</i>) _____</p>
7.	How many adults (aged 18 and over) live in your household (<i>including the respondent</i>)?	_____
8.	How many children (under 18 years old) live in your household?	_____
9.	Is your family registered in a family poverty benefit program (e.g. PAROS)?	<p>3. Yes</p> <p>4. No</p>
10.	In average, how much money does your family spend monthly? Do you need to specify for what expenses?	<p>1. Less than 50,000 AMD</p> <p>2. From 51,000 to 100,000 AMD</p> <p>3. From 101,000 to 200,000 AMD</p> <p>4. From 201,000 to 300,000 AMD</p> <p>5. Above 301,000 AMD</p> <p>88. Don't know/refusal</p>

Thank you, for your time and willingness to participate in our study.

Appendix 2- English guide for health care provider

Understanding the barrier to chemotherapy treatment in breast cancer patients

American University of Armenia

Khachatryan Anush

Guide in-depth-interview for Health care providers

ID:

DATE:

PLACE:

Time:

INterviewer:

Consent Form

Introduction

As I mentioned in the consent form the goal of this study is to better understand the experiences of BC patients during their chemo treatment and come up with potential recommendations for improving BC care. I would like to talk to you about your personal experience in this field.

To begin our conversation, could you please introduce yourself and your work?

Questionnaire

General information on chemotherapy processes.

1. What are your responsibilities in providing care to BC patients?
2. Could you describe how the delivery of chemotherapy treatment is arranged in your health care facility? Who is responsible for delivery of treatment for BC patients in your hospital? How is chemotherapy for BC patients structured and scheduled? How many times does a BC patient receive chemotherapy over the course of their entire treatment? What is the average duration of each round of chemotherapy and the intervals between them?
3. What protocols (clinical practice guidelines) do health care service providers follow for providing the chemo to BC patients? Please describe how these protocols are documented and are taught to health care providers. If there are no protocols, based on what are you making decisions to provide care? How do you decide which drugs to prescribe to the BC patients? *Probe: the drugs which have mild side effects/ which are more or less available/ cheap / very effective.*
4. How is BC patient education conducted in this facility? What educational sessions are available for BC patients in your health care facility? Who is responsible for educating (providing information what to expect during the treatment how to overcome some

side effects etc.) BC patients in this facility? *What is your role in educating BC patients?*

5. How much time, on average, does a single BC patient spend in your facility when receiving chemotherapy? Approximately how many BC patients a day can get the chemo based on the capacity of health care facility such as cabinets, available drugs, and available specialists? Why is there a limit on the number of BC patients that can be managed at this facility? What can you say about the current load of the patients compared to the capacity of your health care facility? *Probe. Do you have more or less patients than the hospital have capacity for?* If the BC patient load exceeds the capacity of your institution to provide care for all patients who are in need, how do you solve that issue?

Cost of care

Now let's talk about the prices of chemotherapy care for patients.

a. FREE DRUGS

Which services and drugs are free? For which services and drugs do the patients have to pay for? How do patients get free drugs? Who is responsible for the provision of those drugs? To what extent are free drugs sufficient given the current demand in your facility? If not sufficient, how do you solve that problem?

b. PAID DRUGS

How do patients get drugs that they must pay for themselves? How much money they have to pay for those drugs? To what extent do patients face difficulties for buying the drugs and how do they solve such problems? What do you suggest to improve the access to drugs for the patients?

- c. How do the drugs that are given to BC patients in your health care facility compare to the drugs that are given in western countries? how are your treatment decisions influenced by the current cost of drugs and care in Armenia?

Overall Quality of the care

6. How often do patients give up the chemo treatment prior to completing it? What are the main causes for which patients interrupt the chemotherapy? What do you do in those cases, when patients want to stop the chemo treatment?
7. What are the main problems in BC care in Armenia nowadays
 - a. For the patients
 - b. The health care service providers
 - c. For the healthcare facilities

What would you suggest improve BC care in Armenia?

DEMOGRAPHIC FORM FOR HEALTH CARE SERVICE PROVIDERS

ID _____

1	Are you a citizen of Armenia?	1. Yes 2. No
2	Where do you live?	1. Yerevan 2. Marze <i>–please specify</i> _____
3	How old are you?	
4	What is your marital status?	1. Married 2. Separated/Divorced 3. Widowed 4. Single
5	Indicate the highest level of education that you have completed?	1. School (less than 10 years) 2. School (10 years) 3. Professional technical education (10-13 years) 4. Institute/University 5. Postgraduate
6	Where do you work now?	_____
7	What is your position?	_____

8	Have you participated in any training since your graduation?	1. Yes 2. No
9	How many trainings did you receive?	-----
10.	When was your last training?	_____
11.	How many years are you working in the field of oncology?	_____
12.	How many years are you working with BC patients?	_____
13.	How many years are you working in this facility?	_____

Appendix 3 – English guide for Family members

Understanding the barrier to chemotherapy treatment in breast cancer patients in Armenia

American University of Armenia

Khachatryan Anush

Guide for in-depth interviews with a family member of a patient with breast problems

ID:

Date:

Place:

Time:

Interviewer:

Consent Form

Introduction

As I mentioned in the consent form, the aim of this study is to learn about the experiences that patients with breast problems and their families have during the treatment. Having a patient with breast problems in your family, means that you are familiar with this issue, and could provide some important information. So I would kindly ask you to answer several questions to help us to learn more about what it is like to be a family member of a patients with breast problems in Armenia. Your answers will help us to provide recommendations to improve the care for patients with breast problems in the country.

To begin our conversation, I would like to ask you to introduce yourself.

Questionnaire:

General Information on processes of care

1. How did you find out about the disease of your family member? How was she diagnosed with breast problems, when and where? How many of her family members are aware of her disease? If none, why? *Probe. Not to burden other family member with the care?/ Not to stress them?*
2. How often have you visited the health facility with your family member for receiving a treatment? *Probe. Only the very first round, from times to times, always.* If you have ever accompanied her, what can you say about the availability of services and of the quality of delivering the treatment at the facility where *she receives the treatment (probe. queues, availability of drugs, cost of services and drugs, attitudes of doctors, side effects, paperwork)?* To what extend are you satisfied with the services? *What would you suggest to improve the quality of services?*

3. *To what extent has [name] resisted taking her treatment for breast problems? In which ways has she resisted? If she does resist, what were the major causes for resisting continuing the treatment? What happened after she resisted? How did she and your family deal with the issue? How big of a problem has this been? How did she and your family deal with the issue?*
4. Who does [name of patient] live with? If she lives alone, who is around her while she's receiving treatment? Probe. *The daughter/son, nurse, sister, brother, husband or other (specify)*. How does the family support her in taking her treatment? Probe: *accompany for getting the treatment, deliver drugs, financial support, other (Specify)*. How did the diagnosis and treatment affect her life and the life of your family?
5. What can you say regarding how she feels after taking the drugs? What side effects does she suffer from from the drugs? How do you/other family members help her to manage the side effects of the drugs?

Cost of care

6. What can you say concerning the drug availability? Which drugs are free and which are not? How are those free drugs provided? What are the difficulties for getting the free drugs? How do you purchase any drugs that are not provided free of charge? What difficulties does your family face in this regard and how do you overcome them?
7. What can you say about financial issues of the treatment? For what services have you paid for? How much money has your family spent on the treatment overall? To what extent your family can afford the treatment expenses? What types of governmental support or other type of support does your family receive?
8. Could you summarize the main problems of treatment for patients with breast problems and for their families in general? What would you suggest to address those problems?

Demographic Form

ID _____

11.	1. Are you citizen of Armenia?	5. Yes 6. No if not what country _____
12.	2. Where do you live?	3. 1. Yerevan 4. 2. Marz → <i>please, specify</i> _____
13.	5. How old are you?	6. 7.
14.	8. What is your marital status?	5. Married 6. Separated/Divorced 7. Widowed 8. Single 9.
15.	10. Indicate the highest level of education that you have completed: 11.	6. School (less than 10 years) 7. School (10 years) 8. Professional technical education (10-13 years) 9. Institute/University 10. Postgraduate 12.
16.	13. Are you employed?	9. Yes 10. Yes, but on maternity/pregnancy leave 11. No 12. Self-employed 13. Seasonal worker or farmer 14. Student

		<p>15. Retired</p> <p>16. Other (<i>specify</i>) _____</p> <p>14.</p>
17.	15. What is your relationship to a BC Patient?	16. _____
18.	17. How many children (under 18 years old) live in your household? 18.	19. 20. _____
19.	Is your family registered in a family poverty benefit program (e.g. PAROS)?	1. Yes 2. No
20.	21. In average, how much money does your family spend monthly? Do you need to specify for what expenses?	<p>6. Less than 50,000 AMD</p> <p>7. From 51,000 to 100,000 AMD</p> <p>8. From 101,000 to 200,000 AMD</p> <p>9. From 201,000 to 300,000 AMD</p> <p>10. Above 301,000 AMD</p> <p>22. 88. Don't know/refusal</p>

Thank you for your time

Appendix 4 – Armenian guide for health care providers.

Բուժման ընթացքում կրծքագեղձի հետ խնդիրներ ունեցող հիվանդների հետ հանդիպող դժվարությունները բացահայտելուն ուղղված հետազոտություն
Հայաստանում Ամերիկայան Համալսարան
Խաչատրյան Անուշ

Բուժաշխատեղների հետ անհատական հարցազրույցի ուղեցույց

Ամսաթիվ:

Տեղ:

Ժամանակացույց:

Հարցազրույցատար:

Համաձայնության Ձև

Ներածություն

Ինչպես նշվեց համաձայնության ձևի մեջ, այս հետազոտության նպատակն է ավելի լավ հասկանալ կրծքագեղձի քաղցրեղով հիվանդների փորձը` քիմիոթերապիայի ընթացքում և ներկայացնելու առաջարկություններ այս հիվանդության համար նախատեսված խնամքը բարելավելու նպատակով: Ես կցանկանայի խոսել ձեզ հետ այս ոլորտում Ձեր անձնական փորձի մասին :

Հարցաշար

Ընդհանուր տեղեկություններ Քիմիաթերապիայի ընթացքի մասին

Որոնք են Ձեր պարտականությունները կրծքագեղձի քաղցրեղով հիվանդներին խնամք մատակարարելու բնագավառում:

Կարո՞ղ եք նկարագրել՝ ինչպես է քիմիոթերապիան կազմակերպված Ձեր հիվանդանոցում: Ո՞վ է պատասխանատու կրծքագեղձի քաղցրեղով հիվանդներին քիմիոթերապևտիկ բուժում տրամադրելու համար Ձեր հիվանդանոցում: Ինչպե՞ս է կառուցված և պլանավորված քիմիաթերապիայի մատակարարումը կրծքագեղձի քաղցրեղով հիվանդների համար: Ինչքա՞ն հաճախ է հիվանդը ստանում քիմիա ընդհանուր բուժման ընթացքում: Ինչքա՞ն է յուրաքանչյուր քիմիա ստանալու միջին տևողությունը և ընդմիջումները քիմիոթերապևտիկ բուժման կուրսերի միջև:

Ի՞նչ ուղեցույցներ են բուժաշխատողները հետևում, երբ տրամադրում եք քիմիաթերապիա հիվանդներին: Իչպես են այդ ուղեցույցները մշակվում և ուսուցանվում բուժաշխատողներին: Եթե նման ուղեցույցները բացակայում են, ապա ի՞նչն էք հիմք ընդունում կրծքագեղձի քաղցրեղով հիվանդներին բուժման մասին որոշումներ կայացնելու դեպքում:

Ինչպե՞ս է իրականացվում կրծքագեղձի քաղցկեղով հիվանդների կրթումը Ձեր հաստատությունում: Կրթական ի՞նչ դասընթացներ կան կրծքագեղձի քաղցկեղով հիվանդների համար Ձեր հաստատությունում: *Æ* Կ՛հարգե՞ք են հասանելի հիվանդներին Ձեր հիվանդանոցում: Ո՞վ է պատասխանատու հիվանդներին կրթելու համար (տրամադրում էք գիտելիքներ թե ի՞նչ ակնկալել բուժման ընթացքում և ինչպե՞ս հաղթահարել կողմնակի ազդեցությունները) Ձեր հիվանդանոցում: Ո՞րն է Ձեր դերը ԿՔ հիվանդներին կրթելու հարցում: Միջինում ինչքան ժամանակ է հիվանդանոցում անցկացնում յուրաքանչյուր հիվանդ քիմիա ստանալու համար: Մոտավորապես, օրական քանի՞ հիվանդ է կարողանում քիմիա ստանալ, ելնելով հիվանդանոցի հնարավորությունից: Ի՞նչ կարող էք ասել ներկայիս հիվանդանոցի ծանրաբեռնվածության և հիվանդանոցի հնարավորության մասին: Փորձ. Արդյո՞ք հիվանդները քիչ են/շատ են քան կարող է հիվանդանոցը սպասարկե՞ն: Եթե հիվանդների քանակը գերազանցում է հիվանդանոցի թույլատրելի սահմանները և հիվանդանոցը ի վիճակի չի լինում բավականաչափ ծառայություններ մատուցել, ինչպե՞ս եք վարվում նման դեպքերում:

Խնամքի արժեքը

Անվճար դեղորայք

Ո՞ր ծառայություններն ու դեղորայքն են անվճար տրամադրվում հիվանդներին: Ի՞նչ ծառայությունների և դեղորայքի համար հիվանդները պարտավոր են վճարե՞ն: Ինչպե՞ս են հիվանդները ձեռք բերում այդ անվճար դեղորայքը: Ո՞վ է պատասխանատու այդ դեղորայքի մատակարարման համար: Ինչքանո՞վ են

անվճար դեղերը բավարարում ձեր բուժ հաստատությունում առկա պահանջարկը:

Եթե չեն բավարարում, ապա ինչպե՞ս եք լուծում այդ խնդիրը:

Վճարովի դեղորայք

Ինչպե՞ս »ՎՃ հիվանդները ձեռք բերում վճարովի դեղորայքը: Ինչքա՞ն գումար են

նրանք պարտավոր վճարել այդ դեղորայքի համար: Ինչքա՞ն հաճա՞Է են

հիվանդները դժվարությունների հանդիպում դեղորայք ձեռք բերելու համար և

ինչպե՞ս են լուծում այդ խնդիրը: Ի՞նչ կառաջարկեք հիվանդների համար դեղորայքի

հասանելիությունը բարելավվելու նպատակով:

Խնամքի ընդհանուր որակը

Ինչքա՞ն հաճախ են հիվանդները ընդհատում քիմիայի բուժումը: Որոնք են

բուժումն ընդհատելու հիմնական պատճառները համար: Ինչպե՞ս եք վարվում

նման դեպքերում:

Որոնք են հիմնական խնդիրները կրծքագեղձի քաղցկեղի խնամքի համար

Հայաստանում:

Հիվանդի համար

Առողջապահության աշխատակիցների համար

Բուժ հաստատությունների համար

Ի՞նչ կառաջարկեիք Հայաստանում կրծքագեղձի քաղցկեղի խնամքը բարելավվելու

համար:

	Հարց	Պատասխան
1	Դուք Հայաստանի քաղաքացի ե՞ք:	Այո Ոչ
2	Որտեղ եք բնակվում:	Երևան Մարզ <i>նշեք՝</i>
3	Քանի՞ տարեկան եք:	<i>Նշել՝</i>
4	Ի՞նչ ամուսնական կարգավիճակ ունեք:	Ամուսնացած Բաժանված Ամուրի Միայնակ
5	Ի՞նչ կրթություն ունեք:	Դպրոց (10 տարուց պակաս) Միջնակարգ դպրոց (10 տարի) Միջին մասնագիտական Բարձրագույն/Համալսարանական ն
6	Որտե՞ղ եք այժմ աշխատում:	
7	Ի՞նչ պաշտոն եք զբաղեցնում	
8	Մասնակցել »՞ ք որևէ դասընթացների ավարտելուց հետո:	Այո ոչ?
9	Քանի՞ դասընթացի եք մասնակցել:	
10	Ե՞րբ եք վերջին անգամ մասնակցել	

	դասընթացի:	
11	Քանի՞ տարի է ինչ աշխատում եք օնկոլոդիգիայի ոլորտում:	
12	Քանի՞ տարի է ինչ աշխատում եք կրծքագեղձի քաղցկեղով հիվանդների հետ:	
13	Քանի՞ տարի է ինչ աշխատում եք տվյալ բուժհաստատությունում:	

Շնորհակալություն Ձեր ժամանակի համար !

Appendix 5 - Armenian Guide for family members

**Բուժման ընթացքում կրծքագեղձի խնդիրներ ունեցող հիվանդների հետ
հանդիպող դժվարությունները բացահայտելու վերաբերյալ հետազոտություն**

Հայաստանում Ամերիկյան Համալսարան

Խաչատրյան Անուշ

Կրծքագեղձով հիվանդի բարեկամի հետ անհատական հարցազրույցի ուղեցույց

Ամսաթիվ:

Տեղ:

Ժամանակացույց:

Հարցազրույցավար:

Համաձայնության Ձև

Ներածություն

Ինչպես նշվեց համաձայնության ձևի մեջ, այս հետազոտության նպատակն է ավելի լավ հասկանալ կրծքագեղձի խնդիրներ ունեցող հիվանդների փորձը՝ կապված քիմիականա եղանակով բուժում ստանալու հետ և ներկայացնել բարեփոխումների առաջարկներ՝ բարելավվելու այս հիվանդության համար նախատեսված խնամքը: Լինելով հիվանդի ընտանիքի անդամ՝ Ղուք ինչ-որ չափով ծանոթ եք այս հարցին և ենթադրում ենք, որ կարող եք մեզ հայտնել կարեվոր տեղեկություններ այդ հարցի շուրջ:

Մեր գրույցը սկսելուց առաջ, կարո՞ղ եք ներկայանալ:

Ընդհանուր տեղեկություններ բուժում ստանալու գործընթացի մասին:

Ինչպե՞ս իմացաք Ձեր հարազատի հիվանդության մասին: Ինչպե՞ս իր մոտ ախտորոշվեց կրծքագեղձի հետ խնդիրներ; Ե՞րբ; Որտե՞ղ; Ընտանիքի անդամներից քան ի՞ հոգի է տեղյակ նրա հիվանդության մասին; Եթե ուրիշ ոչ ոք տեղյակ չէ՝ ինչու: *Փորձ. Որպեսզի չճանրաբեռն ենք ընտանիքի մնացած անդամներին իրեն խնամելու համար/ չանհանգստացնելու համար:*

Ինչքա՞ն հաճախ եք ուղեկցել նրան բուժհաստատություն բուժում ստանալու համար: *Փորձ. Միայն ամենաառաջին անգամ/ ժամանակ առ ժամանակ:*

Ուղղղեկցում եմ/ միշտ: Եթե երբևէ ուղղեկցել եք իրեն, ի՞նչ կարող եք ասել ծառայությունների՝ քիմիա ստանալու մասին այդ բուժհաստատությունում (Փորձ.

Տարածություն, հերթեր, դեղորայքի հասանելիություն, դեղորայքի և

ծառայությունների արժեքը, բժիշկների վերաբերմունքը, կողմնակի

ազդեցություններ, թղթաբանություն) : Ինչքանո՞վ եք բավարարված/ գոհ այդ ծառայություններով: Ի՞նչ կառաջարկ էիք ծառայությունների որակը բարելավելու նպատակով:

Ինչքա՞ն հաճախ է նա (*հիվանդը անունը*) դիմադրել բուժմանը: Ինչպես է նա դիմադրել: Եթե իրապես դիմադրել է, ապա որո՞նք էին քիմիոթերապիային դիմադրելու հիմնական պատճառները: Ի՞նչ եղավ դիմադրելուց հետո: Ինչպես եք Դուք և Ձեր ընտանիքը մոտեցել այդ հարցին: Ի՞նչքանով լուրջ խնդիր է դա եղել ձեր համար:

Ու՞մ հետ է նա (անունը) այժմ ապրում: Եթե միայնակ է ապրում, ո՞վ է իրեն խնամում քիմիա ստանալուց և հետո: Փորձ. Աղջիկը/տղան, բուժքույրը, քույրը, եղբայրը, ամուսինը այլ (նշել): Ինչպե՞ս է իր ընտանիքը սատարում իրեն քիմիա ստանալիս: Փորձ. Ուղղեկցում եք իրեն քիմիա ստանալու/ մատակարարում եք դեղորայքը/ ֆինանսական աջակցություն եք ցուցաբերում/ այլ (նշել):

Ի՞նչ կարող եք ասել իր ինքնազագոհության մասին, դեղորայքից հետո: Ինչպիսի՞ կողմանկի ազդեցություններ է նա ունենում դեղորայքից: Ինչպե՞ս եք դուք և ձեր ընտանիքի անդամները օգնում հաղթահարել այդ կողմանկի ազդեցությունները:

Ի՞նչ կարող եք ասել դեղորայքի հասանելիության մասին: Որոնք են անվճար և որոնք ոչ: Ինչպե՞ս են այդ անվճար դեղերը մատակարարվում : Որոնք են հիմնական դժվարությունները անվճար դեղորայքը ձեռք բերելու համար: Ինչպե՞ս եք ձեռք բերում այն դեղորայքը, որը չի տրամադրվում անվճար: Ի՞նչ խնդիրներ է ձեր ընտանիքը ունենում այս հարցի վերաբերյալ և ինչպե՞ս է հաղթահարում դրանք:

Ի՞նչ կասեիք բուժման ֆինանսական կողմի մասին: Ո՞ր ծառայությունների համար եք վճարել: Ինչքա՞ն գումար է ձեր ընտանիքը ընդհանուր առմամբ ծախսել բուժման

համար: Ինչքանո՞վ է ձեր ընտանիքը կարողանում միջոցներ գտնել բուժման

համար: Ի՞նչ տեսակ՞ պետական կամ այլ տեսակի աջակցություն է ձեր ընտանիքը ստանում:

Կարո՞ղ եք ամփոփել նշելով քիմիաթերապիայի հիմնական խնդրաճշգրտող հետ

խնդիրներ ունեցող հիվանդների և իրենց ընտանիքների համար : Ի՞նչ

կառաջարկ՞իք այս խնդիրները լուծելու համար:

	Հարց	Պատասխան
1	Դուք Հայաստանի քաղաքացի՞ եք:	Այո Ոչ
2	Որտե՞ղ եք բնակվում:	Երևան Մարզ <i>նշեք՝</i>
3	Քան՞ի տարեկան եք:	<i>Նշել՝</i>
4	Ինչ ամուսնական կարգավիճակ ունեք:	Ամուսնացած Բաժանված Ամուրի Միայնակ
5	Ի՞նչ կրթություն ունեք:	Դպրոց (10 տարուց պակաս) Միջնակարգ դպրոց (10 տարի) Միջին մասնագիտական Բարձրագույն/Համալսարանակա ն
6	Աշխատում եք արդյոք;	Այո Այո/ Ֆիզարրակուրդի մեջ Ոչ Ինքնագրադված եմ Սեզոնային աշխատող Ուսանող

		Թոշակառու Այլ. Նշել՝
7	Ո՞րն է ձեր կապը հիվանդի հետ:	
8	Քան՞ի չափահաս է ապրում ձեր ընտանիքում (Դուք ել միասին):	
9	Ձեր ընտանիքը գրանցվա՞ծ է ՓԱԲՈՍ-ի ծրագրում:	
		50,000-ից պակաս 51,000-100,000 100,000-200,000 201,000-300,000 301,000 և ավելին չգիտեմ

**Բուժման ընթացքում կրծքագեղձի խնդիրներ ունեցող հիվանդների հետ
հանդիպող դժվարությունները բացահայտելու վերաբերյալ հետազոտություն**

Հայաստանում Ամերիկյան Համալսարան

Խաչատրյան Անուշ

Հիվանդների հետ անհատական հարցազրույցի ուղեցույց

Ամսաթիվ:

Տեղ:

Ժամանակացույց:

Հարցազրույցավար:

Համաձայնության Ձև

Ներածություն

Ինչպես նշվեց համաձայնության ձևի մեջ, այս հետազոտության նպատակն է ավելի լավ հասկանալ կրծքագեղձի խնդիրներ ունեցող հիվանդների փորձը` բուժում ստանալու վերաբերյալ: Ես պատրաստել եմ հարցաշար ինչը կօգնի բացահայտել այդ դժվարությունները: Ձեր պատասխանները կօգնի ձևավորել առաջարկներ այդ ոլորտը բարելավելու համար:

Հարցաշար

Մինչ սկսելը մեր գրույցը կներկայանա ք: Ինչպե՞ս էք ձեզ այսօր զգում: Որտեղի՞ց էք: Միայնակ էք ապրում թե՞ ձեր ընտանիքի հետ:

Ընդհանուր տեղեկություններ բուժման ընթացքի մասին

Ե՞րբ իմացաք Ձեր հիվանդության մասին: Ինչպե՞ս հայտնաբերեցիք, որ ունեք կրծքագեղձի հետ կապված խնդիր: Նկարագրեք խնդրե՞մ` ինչպե՞ս է ախտորոշվել այդ հիվանդությունը, ե՞րբ, որտե՞ղ, ու՞մ կողմից:

Կարո՞ղ էք ներկայացնել ձեր բուժում ստանալու ընթացքը քայլ առ քայլ: Փորձ. Ո՞ր բուժ. Հաստատությունում?: Ո՞ր մասնագետի կողմից էք ստացել բուժումը: Եթե

փոխել էք բուժհաստատությունը/մասնագետին, ապա ի՞նչն էր պատճառը: Ինչքա՞ն հաճախ էք առնչվում որևէ թղթաբանական աշխատանքի հետ

բուժհաստատությունում: Ինչքա՞ն հաճախ էք ստիպված լինում սպասել հերթական բուժում ստանալու համար : Ինչքա՞ն երկար էք ստիպված լինում հերթի մեջ մնալ

բուժհաստատությունում յուրաքանչյուր բուժման համար: Փորձ. Ժամերո՞վ:

Կախված հերթի երկարությունի՞ց: Ի՞նչ կառաջարկեիք այդ գորընթացը` բարելավվելու նպատակով:

Ստանու՞մ էք բուժում ներկայում: Ինչքա՞ն ժամանակ է ինչ ստանում էք այդ բուժումը: Ինչքա՞ն է յուրաքանչյուր բուժում ստանալու միջին տևողությունը: Հաճախականությունը տարվա կտրվածքով և ինտերվալները հերթական բուժում ստանալու:

Բուժման որակը/ Խնամքի հասանելիությունը

Ի՞նչ կարող էք ասել բուժհաստատությունում ստացած խնամքի ընդհանուր որակից: Ի՞նչն էք համարում ձեր խնամքի լավագույն կողմերից և ինչու՞ էք այդպես համարում: Որո՞նք են հիմնական խնդիրները, որոնց առնչվում էք բուժհաստատությունում: Որո՞նք են ձեր առաջարկները դրանկ բարելավվելու համար:

Տարածություն- մոտավորապես ինչքա՞ն ժամանկ է Ձեզանից խլում հասնելու բուժհաստատությունում ստանալու նպատակով ն : Մոտավորապես ինչքա՞ն գումար էք ծախսում բուժհաստատություն հասնելու համար: Ինչքանո՞վ է տարածությունը խոչընդոտում ձեր բուժում ստանալուն:

Դեղորայքի հասանելիություն - Ի՞նչ կարող էք ասել բուժհաստատությունում դեղորայքի հասանելիության մասին: Ինչքանո՞վ են ձեզ անհրաժեշտ դեղորայքը հասանելի բուժհաստատությունում: Ի՞նչ է տեղի ունենում երբ դեղերը բացակա են:

Բուժաշխատողների վերաբերմունք – Ի՞նչ կարող էք ասել բժիշկների, քույրերի և Ձեզ բուժօգնություն տրամադրող այլ բուժաշխատողների՝ վերաբերմունքի մասին: Ընդհանուր առմամբ ինչքանո՞վ էք Դուք բավարարված այդ ծառայություններով: Ինչպե՞ս կարելի է բարելավվել այդ ծառայությունները:

Ծառայության արժեքը

Ինչ կարո՞ղ եք ասել ձեր հիվանդության համար անՆրաժեշտ ծառայությունների արժեքի մասին: Ո՞ր ծառայությունների համար եք վճարում: Ու՞մ եք վճարում: Ո՞ր ծառայություններն են անվճար:

Որքանո՞վ եք ժամանակին ստանում նշանակված: Ո՞ր դեղերն են անվճար տրամադրվում Ձեզ, ստիպված եք իքնուրույն գնելու: Ինչպե՞ս եք ձեռք բերում այդ դեղորայքը: Ի՞նչ կառաջարկեիք դեղորայքի մատակարարման գործընթացը բարելավվելուն պատասխանելով:

Ինչպե՞ս կգնահատեք ձեր առողջությունը դեղերը ստանալուց հետո: Ի՞նչ փոփոխություններ են տեղի ունեցել: Ի՞նչ կոմնակի ազդեցություններ եք ունենում դեղերը ստանալուց հետո: Ինչպե՞ս եք հաղթահարում այդ կոմնակի ազդեցությունները:

Ինչքա՞ն գումար եք ընդհանուր առմամբ ծախսել բուժման վրա: Ինչպե՞ս կդասակարգեիք ձեր ծախսերը և յուրաքանչյուրի վրա մոտավորապես ինչքա՞ն գումար եք ծախսել: *Փորձեք. Ինչքա՞ն գումար եք ծախսել ա. Ճանապարհի համար բ. Դեղորայքի, գ. Ախտորոշիչ ծառայությունների, դ. Բժիշկների, քույրերի, է. Հավքարարների, գ. Որևէ փաստաթղթերի, է. Այլ ծառայությունների (նշել՝)*.

Խնդրում եմ, պատմեք բուժհաստատությունում բուժում ստանալու համար վճարման գործընթացի մասին: Ու՞մ եք վճարել: Խնդրում եմ նշել որ ծառայությունների համար եք վճարում կատարել ուղիղ դրամարկղում: Ո՞ր ծծառայությունների համար ոչ?

Որտեղի՞ց եք գումար ստանում ձեր հիվանդության հետ կապված ծախսերը հոգալու համար: Փորձ. *Ձեր ընտանիքի ամսական եկամտից: Ո՞վ է Ձեզ ֆինանսապես աջակցում բուժում ստանալու համար: Ի՞նչ տեսակ աջակցություն եք ստացել*

կառավարության կողմից: Ի՞նչ կարող եք ասել այդ աջակցության մասին: Ինչպե՞ս
եք ստացել նման աջակցություն:

	Հարց	Պատասխան
1	Դուք Հայաստանի քաղաքացի՞ եք:	Այո Ոչ
2	Որտե՞ղ եք բնակվում:	Երևան Մարզ <i>նշեք՝</i>
3	Քանի՞ տարեկան եք:	<i>Նշել՝</i>
4	Ի՞նչ ամուսնական կարգավիճակ ունեք:	Ամուսնացած Բաժանված Ամուրի Միայնակ
5	Ի՞նչ կրթություն ունեք:	Դպրոց (10 տարուց պակաս) Միջնակարգ դպրոց (10 տարի) Միջին մասնագիտական Բարձրագույն/Համալսարանական ն
6	Աշխատում եք արդյոք:	Այո Այո/ Ֆիզարրակուրդի մեջ Ոչ Ինքնազբաղված եմ Սեզոնային աշխատող Ուսանող

		Թոշակատու Այլ. Նշել՝
7	Ի՞նչ պաշտոն եք զբաղեցնում:	
8	Քանի՞ չափահաս է ապրում ձեր ընտանիքում (Դուք ել միասին):	
9	Քանի՞ անչափահաս է բնակվում ձեր տանը:	
10	Ձեր ընտանիքը գրանցված է ՓԱԴՈՍ-ի ծրագրում:	
11	Ինչքա՞ն գումար է ձեր ընտանիքը միջինում ամսական ծախսում :	50,000-ից պակաս 51,000-100,000 101,000-200,000 201,000-300,000 301,000 և ավելին չգիտեմ

Շնորհակալություն ձեր տրամադրած ժամանակի համար: Կա՞ որևէ այլ բան, որ
կուզենաք ավելացնել:

Appendix 7 IRB Approval



AMERICAN UNIVERSITY OF ARMENIA
ՀԱՅԱՍՏԱՆԻ ԱՄԵՐԻԿԱՆ ՀԱՄԱԼՍԱՐԱՆ

19 March 2013

PRINCIPAL INVESTIGATOR : Tsovinar Harutyunyan PhD

STUDENT INVESTIGATOR: Anush Khachatryan

TITLE: Understanding the Barriers to Chemotherapy in Breast Cancer Patients in Yerevan, Armenia

SPONSORING AGENCY: None

PROTOCOL #: AUA-2013-005

Tsovinar Harutyunyan PhD and Anush Khachatryan
Via Email: tsovinar@aua.am and anush_khachatryan@edu.aua.am

Dear Dr. Harutyunyan and Ms. Khachatryan

The above referenced protocol and was reviewed and approved by the Chair of the Institutional Review Board of the American University of Armenia using the expedited procedure set forth in 45 CFR 46.110, category 6,7, on 19 March 2013. This study will be due for continuing review on or before 11 March 2014. Annual continuing reviews will be required for this proposal. The proposed study can proceed as it is approved by the AUA IRB. However, please note, the IRB must be kept apprised of any and all changes in the research that may have an impact on the level and type of IRB review needed for a specific proposal. You are required to notify the AUA IRB if any changes are proposed in the study that might alter its IRB status and consent procedures. New procedures that may have an impact on the risk-to-benefit ratio cannot be initiated until IRB approval has been given. Please retain this letter as documentation of the IRB's determination regarding your proposal. Please contact me, at skagan@nursing.upenn.edu with a copy to skagan@aua.am and hmartirosyan@aua.edu , should you have any questions about the information in this letter. Thank you.

Sincerely,

A handwritten signature in black ink, appearing to read "Sarah H. Kagan".

Sarah H. Kagan PhD, RN
Chair, AUA IRB
Adjunct Professor, AUA
Professor of Gerontological Nursing, University of Pennsylvania

40 Marshal Bagramian Avenue
Yerevan, 0019, Armenia
Tel.: (37410) 512526, 512525
Fax: (37410) 512512

300 Lakeside Drive
5th Floor
Oakland, CA 94612
Tel.: (510) 987-9452
Fax: (510) 208-3576

Appendix 8 Consent form for Health care provider

Hello, my name is Anush Khachatryan. I am a graduate student of the Master of Public Health program at the American University of Armenia and I am doing a project to understand the barriers for getting the chemotherapy treatment for breast cancer patients in Armenia.

I am inviting you to participate in an interview for this project because you have been /are working with breast cancer diagnosed women by providing the chemo treatment . I was referred to you by your colleagues and patients at your health care facility. Participating in the study involves answering questions during the individual interview. We can arrange the place and time for the interview that would be most convenient for you. It will take no longer than 30 minutes to complete the interview. Your name will not appear in the report or presentation of the project. Your thoughts and opinions will be put together with what is said by other participants and summarized in the research report. Quotes from what you say may be used in reporting the final project findings but will not be identified by your name or any other personal and identifiable information. I will record the interview and take notes throughout the interview. Do you consent to the recording? My notes and the recording will be stored without any information that will identify you and they will be destroyed at the end of the entire project after we finish analysis.

Your participation in this study is voluntary. There is no penalty if you decline to take part in this project. You may refuse to answer any question or stop the interview at any time.

There is no financial compensation or other personal benefits from participating in the study and there are no known risks to you resulting from your participation in the study. The overall benefit of the study will be the exploration of the existing barriers to people with breast problems, which will serve as a basis for establishing some improvement strategies

If you have any questions regarding this study you can call the Principal Investigator Dr.

Tsovinar Harutyunyan at (37410) 51 25 92. If you feel you have not been treated fairly or think you have been hurt by joining the study you should contact Dr. Hripsime Martirosyan, the Human Subject Protection Administrator of the American University of Armenia (37410) 51 25 61.

Do you agree to participate? Please say YES or NO.

Thank you.

If yes, shall we continue?

Appendix 9 Consent form for the patients with breast problems and their family members

Hello, my name is Anush Khachatryan_____. I am a graduate student of the Master of Public Health program at the American University of Armenia and I am doing a project to understand the barriers for getting specialized treatment for patients with breast problems in Armenia.

I am inviting you to participate in an interview for this project because you/your family member have diagnosed health problems with breast and are waiting for or have already received a specialized treatment. I was referred to you by the physicians/nurses at your health care facility. Participating in the study involves answering questions during the individual interview. We can arrange the place and time for the interview that would be most convenient for you. It will take no longer than 30 minutes to complete the interview. Your name will not appear in any presentation of the project. Your thoughts and opinions will be put together with what is said by other participants and summarized in the research report. Quotes from what you say may be used in reporting the final project findings but will not be identified by your name or any other personal and identifiable information. I will record the interview and take notes throughout the interview. Do you consent to the recording? My notes and the recording will be stored without any information that will identify you and they will be destroyed at the end of the entire project after we finish analysis.

Your participation in this study is voluntary. There is no penalty if you decline to take part in this project. You may refuse to answer any question or stop the interview at any time.

There is no financial compensation or other personal benefits from participating in the study and there are no known risks to you resulting from your participation in the study. The overall benefit of the study will be the exploration of the existing barriers to people with breast problems, which will serve as a basis for establishing some improvement strategies.

If you have any questions regarding this study you can call the Principal Investigator Dr. Tsovinar Harutyunyan at (37410) 51 25 92. If you feel you have not been treated fairly during this study or think you have been hurt by joining the study, you should contact Dr. Hripsime Martirosyan, the Human Subject Protection Administrator of the American University of Armenia (37410) 51 25 61.

Do you agree to participate? Please say YES or NO.

Thank you.

If yes, shall we continue?

Appendix 10 Armenian Consent Form for family members and patients

Հայաստանի ամերիկյան համալսարան

Հանրային առողջապահության բաժին

Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով

Իրազեկ համաձայնության ձև

Բարև Ձեզ, իմ անունը Անուշ Խաչատրյան է. Ես Հայաստանի ամերիկյան

համալսարանի Հանրային առողջապահության մագիստրոսական ծրագրի

ավարտական կուրսի ուսանող եմ: Մեր բաժինն իրականացնում է

հետազոտություն, որի նպատակն է ավելի լավ հասկանալ, թե ինչ

դժվարությունների են հանդիպում կրծքագեղձի խնդիրներով հիվանդները

Հայաստանում իրենց բուժման ընթացքում:

Դուք հրավիրված եք մասնակցել այս հարցազրույցին, քանի որ Դուք/Ձեր

ընտանիքի անդամի մոտ ախտորոշվել է կրծքագեղձի հիվանդություն և վերջին 5

տարվա ընթացքում ստանում եք կամ սպասում եք ստանալու մասնագիտացված

բուժում:

Մասնակցությունը այս հետազոտմանը ներառում է պատասխանել հարցերին

անհատական հարցազրույցների ժամանակ: Մենք կարող ենք նախապես

պայմանավորվել տեղը և վայրը, որտեղ Ձեզ հարմար կլինի մասնակցել

հարցազրույցին: , նախօրոք:

Ձեր մասնակցությունը սահմանափակվում է միայն մեկ հարցազրույցով, որը կտևի

ոչ ավել քան 30 րոպե: Ձեր անունը չի արձանագրվի որևէ տեղ և չի ներկայացվի ոչ

մի զեկույցում: Ձեր պատասխանները մեր հարցերին կնպաստեն այս

հետազոտության իրականացմանը, սակայն միևնույն ժամանակ Ձեր պատասխանները կընդհանրացվեն մյուս մասնակիցների պատասխանների հետ::

Ձեր մասնակցությունն այս հետազոտությանը կամավոր է: Ձեզ ոչինչ չի սպառնում, եթե Դուք հրաժարվեք մասնակցել այս հետազոտությանը: Դուք կարող եք հրաժարվել պատասխանել ցանկացած հարցի կամ ցանկացած պահի ընդհատել հարցազրույցը:

Դուք չեք ստանալու որևէ ֆինանսական փոխհատուցում կամ այլ պարգևատրում հետազոտությանը մասնակցելու դեպքում: Դուք ոչ մի ռիսկի չեք դիմում մասնակցելով այս հետազոտությանը: Հետազոտության նպատակն է բացահայտել հիմնական խոչընդոտները, որ հիվանդները հանդիպում են իրենց բուժման ընթացքում: Հետազոտության արդյունքները հիմք կձառայեն առաջարկելու ծրագրեր բարեփոխումների համար:

Այս հետազոտության վերաբերյալ հարցեր ունենալու դեպքում կարող եք զանգահարել հետազոտության համակարգողին՝ Ծովինար Հարությունյանին (37410) 51 25 92 հեռախոսահամարով: Եթե Դուք կարծում եք, որ Ձեզ լավ չեն վերաբերվել կամ այս հետազոտությանը մասնակցելու դեպքում Ձեզ վնաս է հասցվել, կարող եք զանգահարել Հայաստանի ամերիկյան համալսարանի գիտահետազոտական Էթիկայի հարցերով համակարգող՝ Հոփսիմե Մարտիրոսյանին (37410) 51 25 61 հեռախոսահամարով:

Համաձայն եք մասնակցել (այո կամ ոչ):

Շնորհակալություն:

Կարո՞ղ ենք շարունակել:

Appendix 11 Armenian Consent Form for health care providers

Հայաստանի ամերիկյան համալսարան

Հանրային առողջապահության բաժին

Գիտահետազոտական էթիկայի թիվ 1 հանձնաժողով

Իրազեկ համաձայնության ձև բուժ.ծառայողների համար

Բարև Ձեզ, իմ անունը Անուշ Խաչատրյան է: Ես Հայաստանի ամերիկյան համալսարանի Հանրային առողջապահության բաժնի մագիստրոսական ծրագրի ավարտական կուրսի ուսանող եմ: Մեր բաժինն իրականացնում է հետազոտություն, որի նպատակն է ավելի լավ հասկանալ, թե որոնք են հիմնական խնդիրները կրծքագեղձի քաղցկեղով հիվանդների համար քիմիաթերապիա ստանալը Հայաստանում:

Դուք հրավիրված եք մասնակցել այս հարցազրույցին, քանի որ դուք աշխատել եք կամ աշխատում եք կրծքագեղձի քաղցկեղով ախտորոշված կանանց հետ քիմիաթերապիա տրամադրելու ոլորտում: Մասնակցությունը այս հետազոտմանը ներառում է պատասխանել հարցերին անհատական հարցազրույցների ժամանակ: Տեղը և վայրը, որտեղ Ձեզ հարմար կլինի մասնակցել հարցազրույցին կարող ենք պայմանավորվել նախօրոք:

Ձեր մասնակցությունը սահմանափակվում է միայն ներկայիս հարցազրույցով, որը կտևի ոչ ավել քան 30 րոպե: Ձեր անունը չի արձանագրվի որևէ տեղ և չի ներկայացվի ոչ մի զեկույցում: Ձեր պատասխանները մեր հարցերին կնպաստեն այս հետազոտության իրականացմանը, սակայն միևնույն ժամանակ Ձեր

պատասխանները կընդհանրացվեն մյուս մասնակիցների պատասխանների հետ:
Ձեր մասնակցությունն այս հետազոտությանը կամավոր է: Ձեզ ոչինչ չի սպառնում,
եթե Դուք հրաժարվեք մասնակցել այս հետազոտությանը: Դուք կարող եք
հրաժարվել պատասխանել ցանկացած հարցի կամ ցանկացած պահի ընդհատել
հարցազրույցը:

Դուք չեք ստանալու որևէ ֆինանսական փոխհատուցում կամ այլ պարգևատրում
հետազոտությանը մասնակցելու դեպքում: Դուք ոչ մի ռիսկի չեք դիմում
մասնակցելով այս հետազոտությանը: Հետազոտության նպատակն է բացահայտել
հիմնական խոչընդոտները: Հետազոտության արդյունքները հիմք կձառայեն
առաջարկելու ծրագրեր բարեփոխումների համար

Այս հետազոտության վերաբերյալ հարցեր ունենալու դեպքում կարող եք
զանգահարել հետազոտության համակարգողին՝ Ծովինար Հարությունյանին
(37410) 51 25 92 հեռախոսահամարով: Եթե Դուք կարծում եք, որ այս

հետազոտության ընթացքում Ձեզ լավ չեն վերաբերվել կամ այս հետազոտությանը
մասնակցելու դեպքում Ձեզ վնաս է հասցվել, կարող եք զանգահարել Հայաստանի
ամերիկյան համալսարանի գիտահետազոտական Էթիկայի հարցերով

համակարգող՝ Հոփսիմե Մարտիրոսյանին (37410) 51 25 61 հեռախոսահամարով:
Համաձայն եք մասնակցել (այո կամ ոչ):

Շնորհակալություն:

Կարո՞ղ եմք շարունակել: