LIVING WITH BREAST CANCER:
POLICY PRACTICES AND RECOMMENDATIONS

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This is to certify that we have read this thesis and that in our opinion it is fully adequate, in scope and quality, as a thesis for the degree of Master of Science.

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ABSTRACT

LIVING WITH BREAST CANCER: POLICY PRACTICES AND RECOMMENDATIONS

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The main aim of this thesis is to understand experiences, troubles and needs of women with breast cancer and caregivers. It will also attempt to make evidence-based health and social policy recommendations in order to enhance their quality of life and care. For these ends, current cancer related health and social policies of different countries and Turkey are reviewed and these countries are classified into four groups according to their scores in Human Development index. Also, semi structured in-depth interviews are conducted with 16 women with breast cancer, 7 caregivers from family members and 4 experts in Ankara and Izmir. This study reveals that there are physical, psychological, economic and familial impacts of breast cancer on patients and caregivers. Also, there are several institutional deficiencies which adversely influence the quality of life and care of women with breast cancer and caregivers. Based on findings of the field study and review of ongoing cancer policies from different countries, this thesis recommends evidence-based health and social policy regulations. These recommendations are as follows: introduction of personalized treatment, a regular assistance for housework and cooking, nationwide transportation system, legal arrangements regulating working lives of patients and caregivers, continuous psycho-oncological support and follow-up plans, regular familial therapies, a compulsory training program to develop communication skills of oncology professionals, elimination of inequalities among hospitals, cities and regions in terms of infrastructure and human resources, development of new informative channels, establishment of a national database about the treatment process and an international database including social policy regulations about cancer and also increase the role of social workers in breast cancer treatment process.

Keywords: Women with Breast Cancer, Caregivers, Quality of Life and Care,
Evidence-based Health and Social Policies, Turkey

ÖZ

MEME KANSERİYLE YAŞAMAK: POLİTİKA PRATİKLERİ VE ÖNERİLERİ

Erçin, Hazal
Yüksek Lisans, Sosyal Politika Bölümü
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Bu tezin temel amacı meme kanserli kadınların ve bakım sağlayanların deneyimlerini, problemlerini ve ihtiyaçlarını anlamaktır. Aynı zamanda onların yaşam ve bakım kalitelerini iyileştirmeye yönelik kanıta dayalı sağlık ve sosyal politika önerilerinde bulunulacaktır. Bu amaçlarla, farklı ülkelerin ve Türkiye'nin kanser ile alakalı güncel sağlık ve sosyal politika uygulamaları incelenmiş ve bu ülkeler İnsani Gelişmişlik Endeksi'ndeki sıralamalarına göre dört farklı başlık altında gruplandırılmıştır. Aynı şekilde, Ankara ve İzmir'de 16 meme kanserli kadın, 7 bakım sağlayan ve 4 onkoloji uzmanı ile yarı yapılandırılmış derinlemesine mülakatlar gerçekleştirilmiştir. Bu çalışma meme kanserinin hastalar ve bakım sağlayanlar üzerindeki fiziksel, psikolojik, ekonomik ve ailesel etkilerini ortaya çıkartmıştır. Bunlarla birlikte meme kanserli kadınların ve bakım sağlayanların yaşam ve bakım kalitelerini olumsuz yönde etkileyen birçok kurumsal eksiklikler de bulunmaktadır. Saha çalışması bulgularına ve farklı ülkelerin güncel kanser politikaları analizine dayanarak, bu tez kanıta dayalı sağlık ve sosyal politika önerilerinde bulunmaktadır. Bu öneriler şunlardır: Kişiselleştirilmiş tedavi, ev işleri ve yemek için düzenli destek, ulusal taşıma sistemi, hasta ve bakım sağlayanların iş yaşamlarına yönelik yasal düzenlemeler, düzenli psiko-onkolojik destek ve tedavi sonrası takip planları, düzenli aile terapileri, onkoloji uzmanlarının iletişim yeteneklerini geliştirmeye yönelik zorunlu eğitim programı, hastane, şehir ve bölgeler arası altyapı ve insan kaynakları eşitsizliklerinin giderilmesi, yeni bilgilendirme kanallarının açılması, tedavi sureci hakkında ulusal bir veri tabanı oluşturulması, kanser ile alakalı sosyal politika deneyimlerinin paylaşıldığı uluslararası bir veri tabanı oluşturulması ve meme kanseri tedavisi sürecinde sosyal hizmet uzmanlarının rollerinin artırılması.

Anahtar Kelimeler: Meme Kanserli Kadın, Bakım Sağlayanlar, Yaşam ve Bakım Kalitesi, Kanıta Dayalı Sağlık ve Sosyal Politikalar, Türkiye

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TABLE OF CONTENTS

CHAPTER

APPENDICES

LIST OF TABLES

TABLES

CHAPTER I

INTRODUCTION

Cancer is an umbrella phrase for a large group of diseases that can affect any part of the body. Cancer can be defined as the uncontrolled growth of cells, which arises from one single cell and spreads to distant parts of the body (Cooper, 2000). This transformation process ends in different conclusions in a continuum between pre-cancerous lesion and malignant tumors. Cancer is one of the most vital and widespread illnesses of our time. In the World Health Organization Cancer figures (2015), cancer is demonstrated among leading causes of mortality worldwide, with about 14 million new cases and 8.2 million cancer related deaths in 2012. Furthermore, it is estimated that new cases will rise by about 70% over the next two decades. Similarly, number of deaths due to cancer is also projected to increase to 13 million in 2030. Among cancer types, breast cancer is the most common cancer in women worldwide (World Cancer Research Fund International, 2015). In 2012, nearly 1.7 million women were diagnosed with breast cancer, accounting for 12% of all new cancer cases and 25% of all cancers in women (World Cancer Research Fund International, 2015).

The risk of developing breast cancer, like other types of cancer, increases with age, and in most cases (approximately 80%) breast cancer occur in women over the age of fifty years (Ford et al., 1998; McPherson, Steel & Dixon, 2000). Cancer incidence and mortality show variation among different regions in the world. For instance, in developing countries, breast cancer incidence and mortality rates are lower than most high-income countries (Shulman, Willett, Sievers & Knaul, 2010). Thanks to improved detection techniques, earlier diagnosis and effective treatment procedures, mortality rates have been declining in most highly developed countries within the last 30 years. In fact, the number of women who had survived breast cancer for at least 5 years is higher in more developed countries. While in developed regions women with breast cancer are diagnosed generally after menopause, breast cancer in developing countries is mainly a disease of younger premenopausal women (Ginsburg, 2013). Thus, it is possible to suggest that each region should develop its own cancer related health and social policies to provide more efficient care and treatment. Moreover, regular, organized and reasonable implementation of these policies depends on making the best use of available financial, political and human resources. According to World Cancer Report of 2014, establishment of high standard universal social policies in developing countries would cost more than expected. This is mainly because in these countries, both infrastructure and human resources are not well-developed or sufficient. This also explains why these countries can hardly provide basic cancer treatment.

Actually, Turkey has similar concerns, which can be observed through the data within the official report by the Ministry of Health. According to this report, 17630 women have been diagnosed with breast cancer during 2012 in Turkey (T.C. Sağlık Bakanlığı, 2012). The age distribution of these women shows that breast cancer is mostly seen in women between the ages of 25-49 (34.2%), which is defined as premenopausal range, compared to other age groups studied. Yet, due to the inefficient population coverage in active cancer registration activities (only in 15 cities) beclouds to make coherent estimations. Although health and social policies are not adequate in Turkey, cancer treatment is free of charge for all citizens and all ordinary treatments can be found in health and care facilities (World Health Organization [WHO], 2014). Actually, in Turkey, there are 29 university hospitals (one of them is private), 12 Ministry of Health Educational hospitals, and three cancer centers in private hospitals (Erkoç & Yardım, 2011), that provide detection, diagnosis and treatment.

Early detection, exact diagnosis, and efficient treatment are indispensable to increase cancer survival rates and diminish suffering of patients. In order to ensure earlier detection of cancer, health systems should implement effective and widespread screening systems (Humphrey, Mark Helfand, Chan, & Woolf, 2002). However, access to screening procedures can vary around the world. Actually, most developing countries lack adequate screening equipment. After the diagnosis, cancer patients start their treatment process. There are different treatment options, including surgical procedure, chemotherapy and radiotherapy. Tumor type, stage, and place as well as available resources in the health system determine the technique, quality and frequency of treatment. Indeed, as demonstrated by recent molecular and genetic studies, cancer is a heterogeneous group of diseases, which also shows differences in terms of their diagnosis and reactions to treatment (World Health Organization, 2014). Therefore, detection and treatment procedures should take different cancer types into account. After a long and tiring treatment process, growth of tumor cells mostly stops and the cancer can be cured. And in some cases, abnormal cells might again grow beyond their own boundaries. This means the return of cancer, metastasis.

Breast cancer treatment process has several physical, psychological, social and economic impacts on both patients and caregivers. The most frequently observed physical impacts are pain, hair loss, loss of one or both breasts, lassitude and vomiting. Breast cancer can provoke arm edema which can cause functional impairment and psychosocial morbidity (Erickson, Pearson, Ganz, Adams, & Kahn, 2001). Additionally, alopecia (extensive hair loss) is another traumatic side effect of cancer treatment process (Zanini, Verderame, Cucchiara, Zinna, Alba, & Ferrara, 2012). Further, patients can feel fatigued and exhausted during cancer treatment. This side effect has a direct impact on daily lives of patients, because it is stressful, strenuous, and often difficult to treat (Minton, Richardson, Sharpe, Hotopf, & Stone, 2008). Cancer treatment process deeply influences patient. However, caregiver and other family members of women with breast cancer also experience some difficulties due to the physical effects of the treatment process on patients.

Cancer treatment process has also psychological influence on patients and caregivers. Stress, depression, sadness, and anxiety are the most common psychological impacts of cancer (Turner, Kelly, Swanson, Allison, & Wetzig, 2005). These psychological effects deeply influence the quality of lives of patients and caregivers (Parrish & Adams, 2003; Turner et al., 2005). Indeed, stress and depression experienced during cancer treatment process lead to sharp decrease in their quality of life (Kutlu, Çivi, Börüban, & Demir, 2011). Further, diagnosis and treatment of cancer have huge social impacts on patients and caregivers. Social environment can be source of the basic support in adapting the treatment process. However, in most cases patients and caregivers can diminish their social activities due to changes responsibilities and priorities (Syrjala, Stover, Yi, Artherholt & Abrams, 2010). Hence, breast cancer diagnosis and treatment process have significant social impacts on well-being of patients and caregivers. Cancer is not just a medical irregularity which affects only one person. One can safely claim that diagnosis and treatment significantly impact patients, caregivers and other family members. Although family generally underpins all care, there is a huge lack in comprehensive studies about the role and transformation of family members in the care-giving path of cancer, especially in Turkey. Indeed, although social dimension of cancer care has recently started to be discussed, cancer has generally been neglected in social sciences, except psychology. Thus, there remains a significant lack in cancer literature.

Additionally, cancer treatment has important financial consequences on both patients and caregivers (Timmons, Gooberman-Hill & Sharp, 2012). In some cases, care and treatment can demand huge expenditures from patients and families. But, there are also unpredictable expenditures like transportation and accommodation in a different city. What is more, many patients and families need tangible professional supports in housework and cooking to sustain their everyday necessities. Especially working patients and caregivers can lose their income partially or entirely.

Cancer also has huge impacts on each country’s economic, political and social structure. As mentioned above, cancer incidences are continuously rising all over the world. This increase eventually generates concerns at local, national and global levels (Bloom et al., 2012). Actually, cancer has become one of the most challenging phenomena and in turn statistics regarding cancer patients have started to get more awareness in our period.

Incidence and mortality statistics provide important resource of information. Actually a brief analysis of the foregoing statistics provides general patterns. First, they present a ground for comparison between characteristics and risk of different cancer types and stages. Second, countries may use them in generating health and social policies as a form of need assessment. And third, on a global level, countries and health organizations can benefit from them in regional comparisons and indexes. Yet, statistics are not sufficient. The current studies are particularly concentrated in the fields of medicine, demography and psychology. Techniques and plans of these studies present a broad outline of cancer. But, it is not possible to make any deductions or assumptions from these statistics about the experiences of cancer patients and caregivers. Actually, their experiences, troubles, expectations and needs cannot be shown in these studies. Moreover, in Turkey, any kind of studies on cancer is very limited in both number and scope. Thus, this thesis aims to understand these unearth dimensions.

The central aim of this thesis is to explore and describe experiences, troubles and needs of women with breast cancer and caregivers. I will also attempt to identify suitable, practicable and applicable interventions and recommendations in order to enhance their quality of life and care after breast cancer diagnosis. This thesis has two different parts, in which I used different methods. In the first part, I will try to make an extensive review of cancer related health and social policy practices in different countries. Then I will present a brief analysis of the historical development of health and social policies in Turkey concerning with special focus on cancer policies. And the second part of this thesis is based on a field study. For this part, I conducted semi-structured in-depth interviews with women with breast cancer, their caregivers and experts. These interviews also provided a base for my health and social policy recommendations that consider the participation of users of health and social care in decision making process[1]. Therefore, the findings of my

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[1] The importance of this point was also emphasized by Maslin-Prothero (2003).

in-depth interviews will open a new road to increase participation of stakeholders including patients, caregivers and experts.

Moreover, I included caregivers of cancer patients as participants of my field study because the target of social policies should not be only to enhance the well-being of individuals. Social policies should also target improving the quality of social relations (Becker, Bryman, & Ferguson, 2012). Caregivers have a huge impact on quality of care of women with breast cancer. They can also have a role in how women with breast cancer would experience psychological, social, familial and economic changes. As already stated, cancer care is mainly undertaken by family members and this may lead to some changes in familial relationships. Therefore, a study in this field should also cover the needs, experiences and expectations of caregivers. Moreover, I interviewed experts from different fields to understand the experiences, troubles and needs of women with breast cancer and caregivers. Interviews with experts provided important insights to understand the institutional lacks and deficiencies in cancer treatment process.

However, as presented in all studies, there are certain limitations of this thesis as well. The first limitation is the inability to generalize the results outside of the participants of this study. This is mainly due to the used qualitative technique and small size of the interviewees. Yet, qualitative technique was the appropriate method for this topic as it enabled me to gather intensive and colorful data. Other than that, only one caregiver from each family was interviewed. Therefore, I could not make comparisons between caregivers from the same family and division of care among them. Nevertheless, talking with all caregivers from the same family was impossible due to the availability or willingness of each caregiver to participate in my thesis and also time and resource restraints. Besides, my fieldwork was conducted only in urban centers. Indeed, the troubles and experiences of women with breast cancer and caregivers in rural areas would change the whole picture totally. In order to overcome this limitation, I interviewed cancer patients and caregivers coming from rural areas to big cities to reach appropriate health care. Yet, still experiences and expectations of women with breast cancer and caregivers can demonstrate differences in small cities or rural areas, due to the lack of treatment opportunities and equipment.

Despite these limitations, this study has several strengths. The primary strength of this study is its transdisciplinary approach in which I used a triangulation method. For this end, I analyzed ongoing practices of breast cancer treatment in different countries, the historical development of health system in Turkey, and recent changes in cancer policies. And also I conducted semi-structured in-depth interviews with women with breast cancer, caregivers and experts. The most important feature of this approach is that it is addressing an under-researched area. In fact, there is a very limited literature that concentrates on expectations and needs of women with breast cancer and caregivers in Turkey. Moreover, presenting more detailed information to clarify compound issues triangulation is one of the most effective methods in health and social policies.

Problems, needs and expectations of women with breast cancer and caregivers rarely become an issue of public discussion. In most cases, policy makers and practitioners largely neglect their socioeconomic and socio-cultural differences when formulating social and health policies. Therefore, in this thesis I would like to investigate the possibility of developing evidence-based and inclusive health and social policy recommendations in order to enhance quality of life of them. In short, this study has at least two main contributions. First, it will attempt to activate public discussions about troubles and needs of women with breast cancer and caregivers whose share in the total population of Turkey is continuously rising. A qualitative study with them will prepare a base for future studies. Second, a field study based on experiences and expectations of patients, caregivers and experts from different socioeconomic and socio-cultural backgrounds would help us to develop evidence-based and inclusive policies.

All in all, this thesis is composed of different chapters each of them dealing with different aspects of living with cancer. In the second chapter, I will try to present the methodology of my field study. Additionally, I will focus on the general characteristics of the participants and the details of the fieldwork. This chapter will also include my own fieldwork experiences since these experiences may guide the future studies on the same topic. In the third chapter, I will try to analyze the ongoing practices regarding cancer as noted above. This chapter will start with discussions on cancer treatment. Later, current health and social policies of different countries will be given. These countries will be grouped in terms of their Human Development Index scores. The fourth chapter, after presenting general information about Turkey’s health policies, will concentrate on the transformation of cancer policies in Turkey. The sixth chapter will discuss the findings of my field study. In this chapter, I will try to understand the impact of breast cancer on patients and caregivers. I will analyze these impacts under five headings, namely physical, psychological, economic, familial impacts. Also I will share their experiences and problems stemmed from lack of efficient institutional regulations and practices. And the last chapter will be composed of a short summary of the study and the presentation of key findings. In addition to this, based on my findings I will try to recommend evidence-based health and social policies regarding women with breast cancer and caregivers.

CHAPTER II

DESIGNING A STUDY WITH WOMEN WITH BREAST CANCER AND CAREGIVERS

This thesis aims to understand the experiences, needs and expectations of women with breast cancer and their caregivers. The research problem of this study is formulated as what are the experiences, needs and expectations of women with breast cancer and caregivers during and after the breast cancer treatment. I will try to develop health and social policy recommendations in accordance with these impacts. To study this problem, in this thesis an analysis around the key concepts of physical impact, psychological impact, economic impact, familial impact, and lack of institutional deficiencies are employed. In this sense, this thesis tries to examine the effects of these independent variables on the quality of life of women with breast cancer and of caregivers.

2. 1. How did I Choose this Topic and Why?

During my undergrad years, my aunt and grandmother had breast cancer, which dramatically changed inter- and intra-generational relations within my family, generated huge financial and emotional burden on our close relatives and had also a direct impact on my life. After my graduation, I decided to return to my hometown, Bursa. In my decision, familial responsibilities played a great role because I should have helped my grandmother during her second cancer treatment process. When I look back over my personal and academic life, I realized that my personal troubles were at the same time social issues (Mills, 2000). And then I tried to establish a relation between my familial experiences and social policy issues. Indeed, my personal troubles and experiences found their echoes in this thesis in which I tried to understand experiences, needs and expectations of women with breast cancer and caregivers. We, as a family, experienced three different cancer treatment processes, and saw its huge impact on our familial relationships.

While I was deciding the topic of my master thesis, I wanted to discuss actual and potential consequences and emotional strains of cancer treatment process on patients and their families. And I wanted to analyze how they coped with the difficulties and problems created by lack of evidence-based health and social policies regarding cancer treatment. At first I planned to conduct a field study only with women with breast cancer and their caregivers. Yet the interviews have revealed that in the treatment process, there are several needs that are not provided by the medical institutions and not covered by legal regulations. In the absence of inclusive health and social policies, like Turkey, patients try to overcome these difficulties and strains with the help of their families, if there is a willing caregiver. Otherwise they try to handle all troubles by themselves. Thus, I wanted to interview experts from different fields to comprehensively understand needs of women with breast cancer and caregivers.

In this thesis, starting from the topic selection to data analyses, self-reflexivity[2] helped me to realize that my personal troubles have shaped my position in the field. In other words, I tried to construct an approach in this study not only by using a self-reference to my personal troubles, but also reaching a self-awareness of my role as a caregiver and its links to social problems. Moreover, in order to overcome the bias of interviewees in talking with a stranger about their intimate fears and experiences, I shared my own experience as a caregiver of a cancer family member. Some interviewees talked more openly after learning my background. Some interviewees even told me that now they could understand why I am doing research on this specific topic. I was an insider in common experiences of them due to my previous role in care-giving. However, I was also an outsider due to my new role as a researcher. Although my position as a both insider and outsider helped

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[2] According to Webb, Schirato and Danaher (2002: xiv), “Bourdieu asks researchers to adopt a reflexivity attitude towards our practice, reflecting upon how forces such as social and cultural background, our position within particular fields and intellectual biased shape the way we view the world”.

me through my field study, self-reflexivity also created a limitation. Experiences and biases I have as a caregiver prepared the basis of this thesis from my own stance. However, it was not possible for me to act without prior experiences. Thus, it is necessary to accept that this thesis is not a pure reality, described and analyzed by an outsider, but more kind of a construction in which my own reality is also injected.

To understand the experiences, needs and expectations of women with breast cancer, their caregivers and experts, I used a triangulation method. Firstly, I made a comprehensive literature review about ongoing practices of breast cancer treatment in different countries. Secondly, I examined the historical development of health system in Turkey and touched upon recent changes in cancer policies. In this chapter, I pointed out the lacks in cancer treatment process. And lastly, I conducted semi-structured in-depth interviews with women with breast cancer, caregivers and experts.

2. 2. Reviewing Literature

Policies regarding women with breast cancer show variety across countries. In order to construct a framework for this thesis, I have tried to reach policy implications of different countries towards breast cancer patients and caregivers. For this aim, I have checked search engines using various queries, read policy documents of countries and asked for information via e-mail to several Non-governmental Organizations about their regional policy implications[3]. Nevertheless, I could only reach a limited amount of information about cancer policies, which might provide some insights about the underlying reasons. For instance, social policies aiming to improve qualities of lives of women with breast cancer may be limited. Additionally, language differences created an obstacle for me. Most of the policy documents were written in countries' native languages, thus literature review was limited only to English-written texts. And similarly, the dominance of medical

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[3] I have reached 17 organizations namely; German Cancer Society, Nepal Cancer Relief Society, BreastCheck, Worldwide Cancer Research, Avon Foundation, Health Policy Project, Institut National du Cancer, Macmillan Cancer Support, English Speaking Cancer Association, Cancer Australia, Manx Cancer Help, Cancer Council Australia, American Cancer Society, BreastCancer, Lebanese Breast Cancer Foundation, Susan G. Komen, The New Zealand Breast Cancer Foundation.

discussion in the field of cancer also created a gap of social regulations and needs in the same field.

Regarding the analysis of social policy documents, there is an important point which needs to be mentioned. The majority of the health and social policy documents of different countries contains some concepts representing particular social groups, such as “single mothers”, “unemployed patient”, and so on. Although I would prefer a broader understanding of welfare without oppressive and discriminatory script, in some cases I had to use the same language while writing. Especially in Turkey, there is a huge lack in research about people who were not defined in a disadvantaged group. In order to be a subject of a social or health policy, people should be a member of a disadvantaged social group. Therefore, one should define broader terms which include However, in this thesis; actors are not taken as marginalized social groups. Three different actors, namely women with breast cancer, caregivers and experts are grouped according to their relations with the cancer treatment process. This approach aims to overcome the barrier of language which hides multiple identities and multiple positions. And thus necessitates a research technique that takes into views, needs, experiences and expectations of these actors into account.

2. 3. Why Qualitative Method?

It is a generally accepted fact that both quantitative and qualitative techniques actually reproduce a view about how the social world should be studied. This approach neglects the possibility of mixed method which encapsulates the use of both methods. Actually I largely agree with this statement, I used some quantitative data taken from Turkish National Statistical Institute to understand the overall picture of cancer in general and breast cancer in particular. Quantitative techniques, which put emphasis on directly observable entities, have some advantages in terms of measurement, causality, generalization and replication. Yet, to understand and analyze the experiences and expectations of women with breast cancer and their caregivers, an interactive, face to face, in-depth qualitative research was quintessentially necessary. To focus on actors' attached meanings to cancer and cancer treatment process, one need to make in-depth interviews with participants. If I had conducted a survey or any other kind of quantitative technique, the results would be descriptive without any insights. But my aim in the field study was to understand the feelings, experiences, expectations and perceptions of interviewees. Moreover, the possibility of descriptions and comparisons between contexts also makes qualitative approach as the appropriate form to be used. Maybe the most important aspect of qualitative technique, as stated by Rossman and Rallis, is that collecting qualitative data is not a passive process (2011). In other words, in a qualitative study participants can play a very active role in the interview process, because they can direct the course and content of questions. Moreover, this technique let the interviewer prompt and ask for clarification when it is necessary. Deeper understandings grow through the dialogue of in-depth interviews, as interviewer and participant "*coconstruct*" the meaning together (Rossman & Rallis, 2011, p. 180). In a nutshell, qualitative technique helped me to contextualize the current lacks in health and social policies.

Thus I used the semi-structured in-depth interview technique. I prepared an interview guide organized around the predetermined key areas in order to envelop all chief topics during the interviews. I adapted the order of questions, changed the wording of questions, clarified the meaning of questions, added or omitted questions according to their relevance to the particular interviewee and changed the amount of time given to particular topics. To make in-depth interviews, I mainly used two different types of techniques to reach the interviewees with a purposive method. They were both purposive because I had an intention before going to the field in terms of some pre-determined characteristics for interviewees. Firstly, I applied snowball method by asking each interviewee who else might be relevant and willing to be interviewed. This technique was useful in İzmir, where I conducted interviews through informal channels. Secondly, I used convenience method by interviewing conveniently available people. This technique was used in Ankara, in which formal channels directed me during the data collection process.

However, choosing qualitative method has created some challenges regarding external reliability and external validity. External reliability is about the question of whether the study can be replicated. The answer for this question would be that these interviews are not open to any replication, due to my, as interviewer, position as insider as a caregiver. I was familiar with the experiences and feelings of the interviewees and in some cases my position made some topics more open to dialogue. On the other hand, external validity is about the generalizability of findings to other settings and population. My findings cannot be generalized to other settings due to limited number of interviews and contexts. For instance I have no participants from rural areas. I conducted my interviews in big cities including all treatment devices in their hospitals. In other contexts, such as small cities or rural areas, experiences and expectations of women with breast cancer and caregivers might show differences due to the lack of treatment opportunities.

2. 4. Questionnaire Preparation and Taking Permission

Preparing a questionnaire has different steps. Firstly, one should decide on the subheadings, which necessitates knowledge about the all process. Secondly, types and wording of questions should be decided carefully, especially when studying with vulnerable groups. My personal experiences were helpful for me in this step. I am familiar with the needs and expectations of both women with breast cancer and also caregivers, thus it was easy for me to prepare subheadings. However, this might also be a limitation for me because it could have made me blind to the spaces which have not lived in my own familial life. Additionally, types and wording of questions were also easy to prepare for me, because I lived with a cancer patient for a long time and I am familiar with their emotional strains and fears. However, taking emotions into consideration might create some limitations in some occasions. Some points in questionnaire were especially left untouched due to my prior experiences. In other words, I did not touch upon some areas which might create fear or sadness on participants.

In-depth interviews were conducted within this study in order to reach people’s own explanations and ideas about their own situations. The questions were all open ended. During the interviews, questions regarding these topics were asked to women with breast cancer: demographic questions, pre-diagnosis time use, diagnosis, treatment process, physical, emotional, transportation, psychological and economic needs. On the other hand, caregivers were asked different questions: their responsibilities in cancer treatment process, transformation in their familial relations, feelings and needs regarding their obligations. And lastly, experts were asked particular questions about their own fields. To sum up, each group of interviewees were asked different sets of questions.

After preparing questionnaires, I have applied for ethics committee approval to Middle East Technical University Human Research Ethics Committee. The committee has examined the questionnaire which will be used, and approved my field study. This approval means that professional committee was convinced that this research will not cause any damage on the interviewees. After this approval, I prepared a document for request of permission, which was signed by my thesis supervisor. I have applied to two big oncology hospitals, namely Dr. Abdurrahman Yurtaslan Demetevler Ankara Oncology Education and Research Hospital and Hacettepe University Hospital. Unfortunately, Demetevler Oncology Hospital has rejected my application without giving any explanation for it. Hence, I could not make any in-depth interviews at this hospital. Actually, this rejection was an important indicator of medical authority. Administers take hospitals as their own fields, and do not let patients make any interviews about their own conditions, perceptions and views. On the other hand, Hacettepe Hospital has accepted my request, and helped me during the data collection process. Indeed, they have provided a special room for me to conduct my interviews in privacy. Thus, in my thesis, institutional differences played a major role.

2. 5. Places of Interviews

All interviews were conducted in urban centers of Western Turkey, namely İzmir and Ankara. Western Turkey is the most advanced and developed part of the country and inhabits relatively more educated and skilled people. But, there are marked differences of these urban centers from the rest of Turkey, in terms of population, health equipment and hospital environments. Ankara, capital of Turkey, and Izmir are among the biggest cities of Turkey and they are metropolitan centers which offer diversified health care opportunities and hospitals. Therefore, it was a big chance to observe oncology departments of hospitals in two different cities. Firstly, in İzmir I went to Tepecik Education and Research Hospital, which is the biggest and most developed hospital of Aegean Region. Some in-depth semi-structured interviews were conducted in the garden of this hospital. And the second hospital was, Hacettepe University Hospital, which is one of the most prestigious and developed hospitals of Central Anatolia Region. Both of these two hospitals host patients from the periphery. Moreover, they are both research and education hospitals.

Besides these hospitals, I have found my interviewees through an informal channel as well. As I have mentioned earlier, my aunt had a breast cancer, and she is a member of a nongovernmental organization, namely One Liver One Knower (in Turkish: *Bir Yaşayan Bir Bilen*) composed of women with breast cancer in İzmir. I got in touch with members of this group, and they helped me during my field study. The members of this group have accepted my offer of interview, and we arranged meetings according to their time schedules. They were so helpful and solicitous regarding my topic.

These two contexts had their own characteristics which shaped the data collection process. Conducting in-depth interviews at the atmosphere of hospital has definitely shaped the information gathering practice. The interviews which were conducted in hospital were much more restricted in terms of both the timing and topics to be discussed. Participants were waiting for their doctors or treatment. And in some cases, I conducted my interviews while patients were having their chemotherapy. Additionally, patients were nervous and excited because they were in hospital. Thus, some topics were not easy to be touched upon. On the other hand, the meetings which were arranged through informal channels were much more intimate and peaceful. We could talk about their private experiences, because they were feeling more relaxed due to the atmosphere of our meetings. To sum up, it was not planned to conduct my field study by considering two different channels. But at the end I had a chance to observe different environments. I have used informal channels in İzmir and I had observed two big hospital environments. These particular fields show different aspects of my field study.

2. 6. Semi-Structured In-depth Interviews

The durations of in-depth interviews were changed between 20 minutes to one and a half hours. In İzmir, some interviews were arranged as meetings, thus we talked in restaurants or cafes. On the other hand, in Izmir and Ankara, I conducted interviews in hospitals. In both cases, I could have found no chance to see participants' houses or family lives. This was a limitation for me, because I could analyzed their needs in home by only referring their words. But to observe hospital environment is also important for my master thesis, as mentioned earlier. In some cases, I had chances to wander all steps of a hospital visit. For instance, one of my interviewee asked me to support her during her medical tests. And I accompanied her for an hour as if I was her caregiver or a family member.

Additionally, I had arranged phone and internet interviews. Experts were important actors in this thesis, because they have pointed out some institutional lacks and needs. Yet, psychologists, nurses and other experts who are specialized in cancer care were really busy due to their heavy work load, thus they wanted me to call them and make a phone interview. During these phone interviews, I asked questions about needs and lacks in cancer treatment process in their particular fields. Their answers helped me to analyze the institutional status quo and possible regulations. Additionally, a caregiver has reached me via e-mail. She heard about my thesis in hospital and wanted to be a part of it. But she was living in another city, therefore I sent her the questions and she replied them on an e-mail. Although I had no other choice, the main weakness in my data collection process is these differences in the used techniques. In other words, my in-depth interviews were not conducted in similar and controlled environments.

During the interviews, there were some rules which I tried to follow. For instance, I paid attention to elucidate to the people taking part in the research what the study is about, the risks and benefits of taking part. I referred the main aim of this thesis as understanding the needs and expectations of women with breast cancer and their caregivers. It was stated openly that they can end the interview whenever they want. After this brief explanation, I have obtained their consent before starting interviews with them. Although I showed the informed consent to each participant, I did not want them to sign it because I have never asked about their names or other private information.

In order to avoid missing the important parts of the in-depth interviews, all meetings were recorded and transcribed. I used a digital recorder which provided advanced quality audio, because most of the interviews were conducted in open areas. I explained to interviewees why recording is important and asked their permissions. I made brief notes after the each interview just in case the recording can fail. I did not take any notes during the interviews, because I have kept my eye contact with the participants. This was important to create the frank and warm atmosphere which is a must in such a topic. In other words, especially women with breast cancer were reluctant to remember and talk about all these challenges. Hence, I did not want to lose the intimacy with the participants which might end in their curtailment in interviews. After the field study, all audio recordings were transcribed in full which was a time-consuming activity. But the real challenge in transcription for me to remember and listen all speeches again, because interviews were mostly intimate and gloomy. In some interviews, the participants have cried and mentioned their deep fears and regrets. Thus, transcription was grievous and heartrending for me.

One of the most important strengths of this thesis was the discussion sessions provided by my thesis advisor. All of the transcripts of interviews were read by my thesis advisor and she gave me regular feedbacks during these discussion sessions. Moreover, we arranged a thesis debate group including five other master students in Social Policy department, and shared our experiences of research with each other. These sessions were really helpful for me because some points were enlightened with the help of my advisor and group friends. They lend a hand to me in different parts of the study, for instance preparing questionnaires, categorization and data interpretation.

2. 7. Characteristics of Interviewees

This thesis is mainly based on 27 semi-structured in-depth interviews with three main actors of cancer treatment process. Firstly, I interviewed 16 women with breast cancer. All of them were experiencing different phases of their cancer treatment. This means that while some of them were in their earlier phases of chemotherapy, some others were at the end of their radiotherapy. Their ages range from 34 to 60. Breast cancer generally emerges after menopause, thus most of the respondents were in their fifties. Educational level of respondents is considerably higher than the average level of education in Turkey. More specifically most of them were graduated from high schools and universities. In order to protect their personal information, each participant was named with a color code.

Table 1: Sociodemographic Data of Respondents

Color	Role	Sex	Age	Education	Employment	Marital Status
Crimson	Caregiver (Sister)	Female	51	High School	Self Employed	Married
Gray	Caregiver (Husband)	Male	50	Academy	Retired	Married
Ivory	Caregiver (Husband)	Male	49	Academy	Retired	Married
Beige	Caregiver (Son)	Male	39	University	Informal Sector	Married
Orange	Caregiver (Daughter)	Female	23	University	Student	Single
Brown	Caregiver (Husband)	Male	55	Academy	Retired	Married
White	Caregiver (Daughter)	Female	25	High School	Informal Sector	Married
Pink	Patient	Female	34	High School	Informal Sector	Married
Violet	Patient	Female	43	University	Retired	Married
Lavender	Patient	Female	55	University	Teacher	Divorced
Black	Patient	Female	60	Primary School	Housewife	Married
Maroon	Patient	Female	41	Primary School	Housewife	Married
Orchid	Patient	Female	45	Academy	Housewife	Married
Thistle	Patient	Female	46	University	Informal Sector	Single
Magenta	Patient	Female	43	University	Housewife	Married
Purple	Patient	Female	45	Secondary School	Housewife	Married
Blue	Patient	Female	54	Primary School	Housewife	Widow
Turquoise	Patient	Female	52	Primary School	Housewife	Married
Azure	Patient	Female	54	High School	Retired	Married
Cyan	Patient	Female	46	Academy	Retired	Married
Green	Patient	Female	51	Academy	Retired	Married
Yellow	Patient	Female	53	Primary School	Housewife	Married
Sepia	Patient	Female	60	Academy	Retired	Married
	Oncologist					
	Social Worker					
	Psycho-Oncologist					
	Oncology Nurse					

The second group I interviewed was caregivers. This group is replete with people with different socio-cultural and socio-economic backgrounds. Out of 7 caregivers, there are three women and four men. As mentioned earlier, my interviews were conducted in public spaces and hospitals. This is an important point because it proves the division of care during the cancer treatment process. Care responsibilities of husbands is mostly in the fields of transportation and knowledge accessing. On the other hand physical and emotional cares were handled by female members of their families. Another division of care is based on time opportunities. Most of the caregivers were either retired or students. As a consequence, this care type is handled either by men or unemployed people. Therefore, it would be possible to claim that there is a predetermined division of care during cancer treatment. Thus, as I conducted my interviews with caregivers in hospitals, most of them were men who were responsible for the transportation of their wives or mothers.

And thirdly I interviewed with four experts. One of them was a prominent and popular medical expert, specialized in breast cancer. Additionally, he is the founder of One Liver One Knower social support group. Another expert was a dance teacher of women with breast cancer. His position as a kind of social worker is important in terms of providing a transcendent point of view as both an outsider and insider. He is able to touch upon social care needs of women with breast cancer and their psychological transformation during the treatment process. Thirdly, I had a phone interview with an oncology nurse. She has been working in a prominent oncology hospital for 15 years. Her experiences provided important insights in terms of treatment application process. And, I have reached a psycho-oncologist who works in this special and professional field for long years. She answered my questions and showed the significant role of a psycho-oncologist could play during and after breast cancer treatment process.

2. 8. Data Analysis Process

Every data has a potential to be analyzed in several ways. Similarly, the data including these in-depth interviews have at least three potential analyses, with their own advantages and limitations. The first possibility was a multiple-actor-based analysis. In this way, one can group the answers and experiences under three main groups, such as women with breast cancer, caregivers and experts. The multiple-actor-based analyze have several limitations. For instance, due to the inequality in the numbers of participants from each group narrows down the possibility of adequate evaluation of each group. Moreover, when actors are analyzed in different groups, intersection of process can be blurred. Additionally, caregivers do not form a unique and homogeneous group. In other words, experiences of care giving show differences between people. Transportation and access to knowledge might be the responsibility of husbands, while physical and emotional care can be handled by mainly female members of family.

The second possibility was a process-based analysis. In this way, the answers and experiences can be grouped under subheadings in a continuum of cancer treatment process. In this approach, it is not possible to mention a single and common pattern of phases of treatment shared by all participants. To be more precise, side effects, experiences and needs show differences between patients, caregivers and experts. Thus an emphasis on experiences of different actors is not only a necessity, but also an obligation.

And the last possibility is a combination of these two ways of analysis. I will try to examine the whole process with specific emphasis on different actors and groups. Therefore, I decided on sub-headings including all needs and expectations mentioned by both women with breast cancer and caregivers. The headings can be grouped as physical, psychological, economic and familial impacts of breast cancer and the deficiencies in institutional regulations and practices. These parts will be discussed by referring to views and experiences of those three different actors to avoid leaving some points blank.

2. 9. Studying Vulnerable Groups

Researching vulnerable populations has been a controversial issue due to several reasons. Firstly there are several types of grouping vulnerable populations. For instance, some studies analyze certain vulnerable populations including racial/ethnic minorities, rural area residents or people with poor health status. Some others define this category by referring certain standards in terms of capability in self-explaining. In some cases vulnerable populations contains only children, disabled or elderly people. Although there is a myriad of different definitions of vulnerable populations, the construction of "the vulnerable" as a category is highly problematic. Using "vulnerable" as a category is venturous due to several reasons. Firstly, the term "vulnerable" is itself a value-loaded concept. In most resources, especially in dictionaries, vulnerable means easy to hurt or attack physically or emotionally in dictionaries. Thus, this term implicitly defines the vulnerability in terms of internal traits of a group and largely ignores external factors, including social and historical dynamics that can play a role in creating vulnerability.

Therefore, vulnerability should be understood as a process of being at risk for changed health status as a result of inadequate economic, social, psychological, familial, cognitive, or physical resources (Horowitz, Ladden, & Moriarty, 2002). Indeed, in this thesis, women with breast cancer can be taken as a vulnerable group. They are experiencing a temporary stage due to their illnesses, thus the vulnerability of this group should be defined as a temporary stage. Their perception on vulnerability is rooted in the idea of cancer treatment's ephemerality.

Secondly, social policies mostly consider vulnerable groups as homogeneous and ignore the internal differences and plurality within these groups. There are huge differences among them in terms of age, educational backgrounds, socioeconomic status and family structures. The ignorance of internal differences of a vulnerable group in social policies can exert adverse effects on the lives of members of vulnerable groups. Moreover, researching vulnerable people also has some methodological challenges, such as accessing them, researcher and participant safety and taking their consents. Additionally, harm to an individual and their relationships with others due to a research should be considered at the establishment of the research process. Due to all these challenges, there is a great gap in literature regarding the needs and concerns of vulnerable people. However, giving a voice to vulnerable people can contribute to attempts to empower them and build better opportunities to improve their lives and health (Liamputtong, 2007). Because, a good quality policy making depends on high quality information, derived from a variety of sources including expert knowledge, existing statistics, stakeholder meetings, evaluation of previous policies and field studies with the users (Lin, 2010). Thus, in semi-structure in-depth interviews with women with breast cancer and their caregivers I have paid a huge attention to include respect for their dignity, rights, safety and well-being (Read & Maslin-Prothero, 2011).

CHAPTER III

HEALTH AND SOCIAL POLICIES ABOUT BREAST CANCER

Studies and thesis in the field of social policy commonly contains a chapter namely “best practices”. These chapters generally investigate the health and social policy practices in the most developed countries. However, it is possible to question the possibility of a particular truth that can be designated as the “best practice” across all or various environments. This point of view is open to discussion for several reasons. For instance, “best practices” approach addresses “countries” as its unit of measurement. Health and social policy needs and practices might show differences even among particular regions of the same country. Therefore, I have chosen the heading “Health and Social Policies about Breast Cancer” for this chapter. By choosing this heading, I accepted the fact that there is no possibility to develop the same set of policies which can be implemented to all countries with the same consequences. Yet, all health and social policy documents regarding breast cancer are representing countries. There is a huge diversity in health and social policies about cancer among countries. Actually, there was an important limitation in my research process. While health policies of the most countries can be accessed easily, social policies regarding cancer treatment process generally remains in dark. Although it is known that some countries achieve comprehensive and supportive social policies during cancer treatment process, often it was not possible to reach a written text. In fact, there can be several underlying reasons of this lack. Firstly, social policies regarding women with breast cancer may be limited. In some countries the social dimension of cancer is ignored and neglected in policy discussions and practices.

Another reason could be that there is little or no demand for such information, neither by policy makers nor by the general public. In this respect, there can be some implications regarding women with breast cancer and caregivers, but the information has not been emanated or has not become widespread. The third reason might be any language barrier. I could only analyze the English texts, which mainly come from English-speaking countries, such as the United Kingdom, the United States, Canada and Australia. In other countries, most of the policy documentations were written in their native languages, and this situation made it impossible to reach their policy practices for a researcher who does not know their native languages. Actually, in several cases I learned informally that some countries have detailed practices on this topic; however, I could not reach any formal information about them. For instance, a Turkish immigrant living in Belgium who had cancer treatment said to me that the government was responsible for providing tangible support in housework such as cleaning and cooking to cancer patients. This service is mainly based on a means-testing technique and provides a rate of copayment for these patients. However, although I have reached this information informally, I could not find any formal document about it written in English. Thus I assumed that these kinds of practices have not been made available for international access yet.

Finally, the last reason might be the dominance of medical treatment in this topic, which is an acceptable situation. In the relevant literature, the authors are predominantly from the medical domain, providing information in the form of statistics, comparisons between countries or regions, periodic differences, reasons, results, different kinds of cancer, treatments and some NGO's approaches on it like World Health Organization. Additionally, researchers from the psychology discipline have also written on this subject, but they treated this subject as an extension of the medical treatment. Their approaches provide important insights about psychological needs and supports of patients and caregivers. In the other fields of social sciences, cancer has been discussed occasionally by social politicians, sociologists, and economists. They largely analyze welfare regimes, health reforms and social insurance systems. In other words, these analyses focus more on macro level. In this thesis, I intended to gain an enhanced understanding of the needs of women with breast cancer apart from the procedural medical treatments they receive. Thus, I tried to consider women with breast cancer as an individual and social being, not a medical object, because, cancer’s impact is not solidly seen on patient’s life, it affects all family members both economically and psychologically.

3. 1. Recent Changes in Cancer Discussions

Breast cancer is currently the most common cancer among women worldwide and seems to protect its position in the predictable future (Jemal, Bray, Center, Ferlay, Ward, & Forman, 2011). As a result of this frequency, governments have stroke into cancer policies recently. Now there is a paradigm shift in cancer discussions, with a more inclusive approach to social parts of the treatment process with special focus on the quality of life of both patients and their families. To be more specific, in the new approach, social determinants of health have gained importance. This renovation can be seen obviously in the high-quality care emphasis of the Organization for Economic Co-operation and Development (OECD). Due to the fact that cancer is the second leading cause of mortality in the OECD countries, its latest health policy interrogates how to design a cancer care system to guarantee a high quality care which is always accessible to all cancer patients (OECD, 2013). For that purpose, four main policy areas were designated to improve the quality of breast cancer care, including staying healthy, getting well, living with illness and end of life wellbeing. Similarly, delivery of a standardized evidence-based cancer care is accepted as the major necessity to ensure a high quality of care to all patients, through means of clinical guidelines, multidisciplinary care services and health services evaluations. Yet, quality assurance is provided by a quantitative approach reviewing regular performance data to recognize areas of improvement and deficiency, and providing feedback to providers. In a quantitative approach, it is inevitable to neglect important points because it is mainly based on statistics and generalizations. Subjective measures have not generally been used in this approach which is the only way to understand the quality of life and care of the cancer patient and caregivers. Still, quantitative approach on quality of life discussions is understandable, because cancer treatment is itself costly. Thus any extra expenses rooted in the qualitative studies might create a burden in budgets of countries.

Even in high-income countries, costs of delivering high-quality equitable cancer care present a growing challenge to national budgets. The existing inequality in expenditure for cancer care between countries is growing. For instance, the United States spends around 100 € per resident, while this number is 196 € in Europe (Aggarwal, Ginsburg & Fojo, 2014). Within European countries, now there is a new trend of cutting health budgets, for example Greece cut its health budget by 23.7% between 2009 and 2011, and Spain cut it by 14% in 2012 under the name of efficiency due to their economic crisis. Yet, in some other countries, health system protects its primary position within the national budget. For example, Denmark has separate national health taxes, with healthcare budgets set yearly through conciliation between central administration and local boards (Brown et al., 2014). These differences between countries are reflected in the disparities between health outcomes of the cancer patients. To overcome these inequalities, World Health Organization has tried to establish a criterion for cancer treatment which will be discussed in depth below.

3. 2. Human Development Index

There are many different indications to measure social development level of countries; such as Life Satisfaction Index, Happy Planet Index, Status of Women and Global Gender Gap Index. Moreover, United Nations have introduced four indications on the same issue, such as Human Development Index (HDI), Human Development Index based on Gender, the Index of Gender Reinforcement and Human Poverty Index. These new approaches opened a new debate by recommending that human development includes more than just economic development. Before this approach, the particular purpose and measure of national development was growth of Gross National Product per capita (Kelley, 1991). Since 1990s, HDI is largely used to measure quality of life in different countries. The biggest contribution of this index is its effort on expansion in the focus of economic development to human well-being and quality of life (Sagar & Najam, 1998). HDI is calculated and updated per annum and analyzes countries in a report.

Human Development Index, formulated by the United Nations Development Program, is based on a comparison and measuring of three different arenas of human development, namely longevity, knowledge and access to resources (Hicks, 1997). For these three dimensions, this index has chosen proper indicators; specifically, life expectancy at birth, expected years of schooling, literacy rate and gross national income per capita. Although HDI added new dimensions to traditional economic and financial indicators, there are some expected critical modifications to the HDI. For instance, each dimension should be treated equally and inequity should be considered in each dimension (Sagar & Najam, 1998). Moreover, new dimensions including social disparities and regional differences should be added to measure the development rates of countries.

Human Development Index generally divides countries into four sub-headings according to their HDI value calculated according to dimensions mentioned above. The first heading is Very High Human Development Countries, values of which changes between 0,944 and 0,802. Most of the European Union countries United States of America, Canada and Australia are in this group. High Human Development group includes Belarus, Cuba, Islamic Republic of Iran, Turkey, Brazil and so on. Their HDI scores are between 0,798 and 0,702. The third group, medium human development, ranges between 0,698 and 0,555 and contains Egypt, Indonesia, South Africa, Iraq, Morocco, Zambia, Bangladesh and so on. And the last group is Low Human Development group, values of which ranges between 0,548 and 0,348. This last group embraces most African countries, Pakistan, Angola, Madagascar, Rwanda, Sudan and so on. There are country examples from each group in order to make it easier to compare them. Before analyzing specific examples from each group, I would like to mention general characteristics of them regarding their health and social policies about cancer care.

All countries in high human development group have well-developed infrastructure and human resources for cancer treatment. They have also well-organized social policies about cancer, but these policies are generally based on means-testing. On the other hands, countries in high human development group have their own national health insurance schemes with different coverage conditions and practices. Yet, cultural, religious and social differences play a major role in cancer care consequences. Actually, they mostly have the basic infrastructure and human resources. But they generally experience great problems in terms of public awareness about cancer. Generally, in medium group, there is a shortage in infrastructure and human resources as well as in population-based cancer registries. These shortages have important consequences for both diagnosis and treatment. And lastly, countries of low human development group have severe shortages in infrastructure and human resources. Also they have to struggle with infection-related illnesses. Thus, a combat with breast cancer is not among their priorities. Still, countries from each human development group will be discussed in depth below. The details of countries within these four groups can be seen in the table as follows:

Table 2: Country Groups According to Human Development Index Scores

	Rank	**Country**	**HDI**	**Life Expectancy at Birth**	**Public Health Expenditure (% of GDP)**
Very High	2	Australia	0,935	82,4	9
	4	Denmark	0,923	80,2	10,6
	6	Ireland	0,916	80,9	8,9
	8	USA	0,915	79,1	17,1
	9	Canada	0,913	82	10,9
	14	UK	0,907	80,7	9,1
	17	Republic of Korea	0,898	81,9	7,2
	22	France	0,888	82,2	11,7
High	62	Malaysia	0,799	74,7	4
	69	Iran	0,766	75,4	6,7
	72	Turkey	0,761	75,3	5,6
	75	Brazil	0,755	74,5	5,6
Medium	116	South Africa	0,666	57,4	8,9
	130	India	0,609	68	4
	140	Ghana	0,579	61,4	5,4
	142	Bangladesh	0,57	71,6	3,7
Low	145	Kenya	0,548	61,6	4,5
	151	Tanzania	0,521	65	7,3

Note: Prepared with information retrieved from http://hdr.undp.org/en/countires. Accessed on 24 December 2015.

As an important part of this thesis, this chapter will try to provide some insights about ongoing health and social policies concerning women with breast cancer. With this aim, countries from each level of development will be chosen and exemplified. However, very high human development group shows differences regarding their policies on this issue. Thus it will be divided into two sub-groups according to their commonalities in social and health policies. Under this route, countries from European Union will be discussed firstly. To be more precise, National cancer strategies will be analyzed to get a clearer picture of the general framework within the European Union. In relation to this, the European Partnership for Action against Cancer will be introduced to show the new paradigm of the Union. The second faction of very high human development consists of the United States of America, Australia and Canada. After giving some references from the approaches in the very high human development countries, other levels of countries will be analyzed. In the high human development, cancer related health and social policies of Islamic Republic of Iran, Mexico and Brazil will be examined. In the medium human development, South Africa, Ghana and Bangladesh will be studied. And lastly, Kenya, United Republic of Tanzania and Nigeria will be evaluated as exampled as low human development countries.

3. 2. 1. Very High Human Development

3. 2. 1. 1. EU Approach

World Health Organization published the National Cancer Control Programs, Policies and Managerial Guidelines in 2002 to suggest a strategic image of how the struggle against cancer should be carried on (WHO, 2002). WHO defined National Cancer Control Programs as designed to diminish cancer frequency and mortality and improve quality of life of cancer patients (Albreht, Jelenc, & Gorgojo, 2013). This guideline had a broad repercussion in policy regulations of other countries. In other words, national cancer policies grew massively, particularly in Europe. The first National Cancer Plans were introduced in Denmark, England and France focusing on consistent and equal access to high quality care. Now, most countries in Europe have their own national cancer strategies with some differences. For instance, cancer policies in Italy and Netherlands recommend establishing quality criteria for cancer care and try to evaluate quality standards of cancer care. Likewise, Belgium, England, Estonia, Ireland, Scotland, Switzerland and Wales propose a preamble of guidelines and national standards of quality of cancer care (Atun, Ogawa, & Martin-Moreno, 2009).

Although National Cancer Control Programs have standardized high quality care, their recommendations are not active steps taken to bring forth concrete results, but they are policies that cannot leave the paper and meet the real world. This is mainly because they do not clearly declare how fairness, effectiveness and patient responsiveness goals will be met. More specifically, in Belgium, there is an aim of education for health professionals about improving their communication skills with patients and their relatives. Moreover, diagnosis is expected to be announced with the protocol of a group of experts (Belgium National Cancer Plan, 2008). Additionally, the same cancer plan recommends lump sum payment for patients who lose their hair following cancer treatment. These are practical suggestions determined carefully. On the other hand, Cyprus takes the fight with cancer by using another approach in its national cancer strategy. It calls the activation and participation of civil society for ensuring the high quality care for cancer patients (Cyprus National Cancer Control Strategy, 2009). However, as can be seen in these examples, suggestions are not concrete and definite. Thus, the main actors who will be responsible for the supervision of the whole process are not fixed and specific.

All these differences in recommendations may be a sign of the underlying divergence in funding, policies and access opportunities. For instance, the national cancer strategies of 21 countries have included psychological dimension of the treatment process, but only 10 countries have reserved a budget for it, and only 8 countries have nationally recommended psychological care guidelines (Borras & Prades, 2014). Cancer control strategy for Poland takes the quality of life notion in a broader perspective including the struggle against social stigma and exclusion. Furthermore, it tries to expedite the process of the patient going back to full social and occupational activity. For this purpose, it defines the roles of both professional and unprofessional caregivers, namely those of social care workers, volunteers, neighbors and the general community (Cancer Control Strategy for Poland, 2014). This example indicates how intangible the recommendations they provide, because it does not employ particular workers in this struggle.

To provide a framework for cancer care, in 2009, European Union launched a joint action including member states, with similar needs and different experiences in cancer policy, which is called the European Partnership for Action against Cancer (Gorgojo, Harris & Garcia-Lopez, 2012). With this initiative, heterogeneous national cancer programs were tried to be united or integrated under a homogeneous umbrella. The full implementation of national cancer programs was one of the major aims, in addition to its detailed targets and timeframes, close monitoring of progress, achievement of medical strategies and enforcement of quality control procedures.

As a consequence of this expansion of the care definition, cancer care has become increasingly multifaceted due to the number of disciplines that should be concerned; and without this consideration, it would be inevitable to avoid miscommunication, poor organization and an increase in the fragmentation of services (Albreht, Martin-Moreno, Jelenc, Gorgojo & Harris, 2015). Within this framework, multidisciplinary teams (MDTs) are seen as the best approach to organize cancer care, because this approach brings together healthcare professionals from each related branch involved in cancer diagnosis and treatment. From now on, MDTs are accepted as practical requirements for optimal management, because a fragmented health care organization is considered inadequate when addressing the complex needs of cancer patients. As one of the foremost requirements of cancer patients, psychological needs are ensured by psychosocial oncology care services, because cancer and its treatment have a momentous power on the quality of life of patients, their families and caregivers. For this purpose, the European Guide for National Cancer Programs regards couple/family counseling and spiritual/psychological counseling as necessary. This policy is accepted as an essential mechanism of effective cancer treatment with providing the care they need and also deserve (Borràs et al., 2014)

In the policy statement of EPAAC, cancer care is emphasized as a process which undergoes a paradigm shift from a disease-focused management to a patient-centered approach (Borràs et al., 2014). In this new attitude, new concepts become crucial, such as psychosocial support, quality of life, rights and empowerment of patients. It has been decided that patients will be included in the treatment decision process and their preferences will be taken into consideration. Furthermore, in order to minimize the healthcare disparities across countries with unacceptable outcomes in quality of life of patients, use of clinical guidelines are goaded (EPAAC, 2014). These comprehensive clinical guidelines are analytically developed statements to aid practitioner and patient judgments about suitable health care for detailed conditions. This new approach can be called "patient-centered" because patient empowerment is the key concept in this process as it gives the responsibility to patient for managing their own condition. The paternalistic role of the medical doctor in the decision-making process affecting patient has been questioned by a growing movement on patient self-sufficiency and involvement in health care (Ganz, 1994). As a result of this statement, patient-empowerment and support for families have been offered in nine countries, namely Belgium, Denmark, Germany, Hungary, Malta, the Netherlands, Spain, Sweden and England.

In Denmark in addition to the support for families, the relatives of cancer patients are assured to get support. This approach is important because families of patient might also feel unprepared to cope with this life-changing event (Lethborg, Kissane & Burns, 2003). In the new phase, family members take a new role as caregivers. Any policy, excluding family members would be insufficient, because although patients suffer and are treated as individuals, the reality is that cancer is a community disease (Lakdawalla, Sun, Jena, Reyes, Goldman & Philipson, 2010). For instance, according to a study conducted with 107 close relatives, there are some unmet needs of relatives (Schmid-Büchi, Borne, Dassen & Halfens, 2011). The highest ranked unmet need concerning emotional and support arrangement is to find time for themselves and regarding practical help is “o find help with housework. Moreover, patient-centered health care is critical to overcome the racial, ethnic and economic disparities. Additionally, it is expected to decrease cost and increase quality of care for patients (Epstein, Fiscella, Lesser & Stange, 2010).

With a similar perspective, the United Kingdom has recently transformed its policy and passed on to a different phase of care. This new era requires localization for care and support services. The government launched a national minimum threshold for qualified needs and put a great emphasis on personalization of those needs (UK Department of Health, 2014). In the new Care Act some personalized needs can be undertaken by organizations of the government such as help with housework and gardening and gym membership (CarersUK, 2014). Besides them, travel costs are also included in the low income scheme of the national health system, yet in this part again an eligibility criterion is applied (Tyson, 2010). Although government has such a vital purpose, these aims are not nationally inclusive and the healthcare system still has some deficiencies. Cancer care is an expensive application which every cancer patient is to pay around £35.000 for their treatment process (HM Government, 2012). The means-testing approach sets an asset limit, and decides personal payment according to this rate. During this process, local committees assess the required care and predictable imbursement for that care. Now, under the name of personalization of care and support, payments are promised to be based on needs rather than disease (National Collaboration for Integrated Care and Support, 2013). Nevertheless, England’s Care Act is still seen as an effort to endorse privatization by excluding basic needs from their schemes and applying eligibility criteria (Krachler & Greer, 2015). The legitimation of this regulation lies under the purpose of rising quality and reducing costs.

A law commission has been established to analyze these recent changes in legal regulations on care and support. Unfortunately, their report has indicated that all these laws are mystifying and tricky and can be comprehended adequately by neither the patients nor their caregivers (Department of Health, 2012). The framework of this commission includes that care should render patients more independent, and give control to them over their treatment process. Similarly, the Care Act has also been analyzed and criticized considering its implementation. For instance, the definition of “well-being”, which is the ultimate aim in the care process, is not tangible within these legal regulations. In other words, such a subjective concept cannot be considered in such an abstract manner if the aim is to implement a realistic attitude. There should be a concrete definition of it.

In Europe, when government falls short, some non-governmental organizations take responsibility for needs of cancer patients in addition to medical treatment. As a good example, Irish Cancer Society, a charity in Ireland, tries to give door-to-door transportation service for medical treatment. In Care to Drive program volunteer drivers carry the patient with their personal cars. Also, Travel2Care is another transportation assistance fund constituted by NCCP and aims to support people with legitimate monetary trouble in affording expenses of travelling for treatment. For the purpose of improving cancer care, Nordic Cancer Union has been founded with the participation of members from Danish, Swedish, Finnish, Norwegian and Faroese Cancer Societies (The Nordic Cancer Union, 2012). Each of these organizations is effective in fight against cancer in their countries. For instance, the Danish Cancer Society aims to achieve the empowerment of patients by building seven counseling centers. The Cancer Society of Finland, on the other hand, has established an interactive website for group-chat which enables patients to share their experiences, emotions and fears. Yet, these organizations are run through donations and they generally do not take any fund from governments. Additionally, some non-governmental organizations conduct and fund studies about health systems and well-being of cancer patients. For instance, MacMillan Cancer Support is a well-known charity in the United Kingdom and supported a study which has returned the finding that a plethora of cancer patients experience deprived health and wellbeing following cancer and cancer treatment (Elliot et al., 2011).

As an important impact of a chronic illness, labor market attachment of women with breast cancer has been analyzed to see the inner dynamics of treatment process. In Europe, almost every country provides paid sick leave for an employee treated for cancer (Heymann, Rho, Schmitt & Earle, 2009). As a result of this enforcement, even though patients have a break during their treatments, they habitually go back to their work and continue their careers after their treatment process. As happened in Denmark, some women with breast cancer experienced at least one week of unemployment in the 2 years following breast cancer, yet 81% of patients were still part of the work force after the treatment (Carlsen, Ewertz, Dalton, Badsberg & Osler, 2014). This study shows the importance of a well-designed and well-structured work-related policies.

United Kingdom is highly determined in protection of its citizens with breast cancer in their work lives. The Equality Act 2010 protects cancer patients living in England, Scotland or Wales from being treated unfairly at work. Cancer patients living in Northern Ireland is protected by the Disability Discrimination Order of 2006. In these countries, people with cancer are legally classed as disabled, and these acts indicate employers to make evenhanded adjustments to both work places and working practices. Some examples for these attunements might be giving time off for medical appointments, changing job descriptions, arranging more flexible hours, giving extra breaks, changing performance targets, changing working place (in case of breathlessness makes it difficult to climb stairs) and allowing patient to return work after a long period of time off work. Therefore, it is possible to claim that U.K. has protective and well-designed work policies for citizens who have breast cancer.

3. 2. 1. 2. United States, Australia and Canada

Commonly called ObamaCare, Affordable Care Act, signed on March 23, 2010, established the minimum standards for health insurance policies. Now, this law requires insurance companies to include all applicants within the minimum standards and offered the same rates not considering of preexisting circumstances like chronic illnesses or familial health history. However, this new regulation has excluded tobacco users from some benefits (Martin, 2015). Although discourse of this new aim was inclusive and egalitarian, tobacco using has been seen as a personal habit which user should take all the responsibility. Private health insurance became mandatory, for who cannot be eligible for government insurance. There are two types of government inclusions: Medicare is for people above 65, children and disabled (14.3% of the insured people). And Medicaid covers the most economically disadvantaged part of the society (14.1% of the insured people) (Durmuş, 2015). Moreover, because 23 states discarded the federally financed extension of Medicaid, approximately 30 million citizens will continue to be uninsured (Printz, 2014). Also, low income women with breast cancer can be included to Medicaid, only if she was diagnosed through the National Breast and Cervical Cancer Early Detection Program which is a free or low cost screening program (American Cancer, 2015). Although this inclusion might be helpful for women in detection cancer early, uninsured women's situation is still a controversial issue. Furthermore, nowadays in the States hospitals offer shorter hospital reside. This change increases the burden of informal care, especially provided by family members.

Family is commonly the chief responsible in care-giving process. National Cancer Institute gives some advices for caregivers such as talking with a priest, pastor or spiritual leader, and praying or meditating (National Cancer Institute, 2014). Furthermore, daily needs are accepted as areas which community can help, such as cooking, cleaning, shopping, yard work, childcare, elder care, sharing feelings, driving and so on. This booklet provides advices for informal ways to take support which shows the lack of the formal support provided. More importantly, care is defined in a different way in each state, and there is a lack of comprehensible description. Although, the Affordable Care Act tries to reach a more collective approach to helping every citizen, accomplishment of the act can be unfair for some people. To be more precise, a given diagnosis is generally attached to a specific procedure with no regard to individual dissimilarities (Chandra, Crethar & Hall, 2014).

Needs of the cancer patients do not end with the treatment process. Currently there are more than 13 million cancer survivors in the United States (McCabe et al., 2013).

Numerous of patients will need preventive and medical care following to their cancer care. There is a need for a standardized regulation for care, because there are no unvarying standards for the care of survivors. Recent studies indicate that 25% and 10% of cancer survivors states that they have poor physical and mental health related quality of life compared with only 10% and 6% of the adults without cancer (Weaver et al., 2012). Therefore, health system of U.S. should immediately develop a standard for care and treatment of cancer to increase the quality of lives of cancer patients.

In quality of life approach, home care and personal care are mostly referred two dimensions. United States government can ensure home care services such as physical therapy, emotional and spiritual care, help with preparing meals, only if the patient is eligible for the help (National Cancer Institute, 2015). As mentioned earlier, Medicare and Medicaid are the main government-run insurance programs and might cover part-time home care. However, these programs are based on means-testing approach and do not include all citizens. Still, some Medicaid programs can provide funds to pay family members for caring the patient. This care may only be substituted by paid professionals or more expensive facilities. On the other hand, private insurance companies also might comprise some short-term home care services, and generally excludes personal care from their plans. In USA, mostly used way for services is self-pay. In other words, for services of long-term personal care, patient or her caregiver are expected to pay out-of-pocket payment. Last help comes from community organizations, like nongovernmental organizations and social support groups.

In USA, non-governmental organizations provide help in some basic needs. For instance, Adventist Home Health is a faith-based non-profit organization and helps cancer patient and her family (Adventist Health Care, 2015). Their certified nursing assistants provide home care services, such as laundry, meal preparation, companion, shopping and housekeeping. However these services are not free of charge. Other nationwide community-based voluntary organization is the American Cancer Society (American Cancer Society, 2015). The major contribution of this organization is overnight accommodations to cancer patients based on eligibility requirements. Another way to find personal care services is home care agencies which can be covered by Medicare and Medicaid. If the patient is not eligible for these insurance systems, she should make some payment for these services. Non-profit organizations more tend to give emotional support and advices instead of financial and tangible support. Similarly, in Australia, non-governmental organizations share the responsibility with government. As the major cancer care association, Australia Victorian Government Initiative, which was founded in 2006, has a well-established approach to support care. They put a great emphasis on person and family centered approach to care (Department of Human Services, 2009). This organization prioritizes multidisciplinary and supportive care.

When a patient is not eligible for governmental insurance programs and cannot be assisted by any nongovernmental organizations and social support groups in their neighborhood, all responsibility falls to her close family members and relatives. Emotional support is the most common endorsement supplied by caregivers (Romito, Goldzweig, Cormio, Hagedoorn & Andersen, 2013). Although most of them lacks of a proper guidance and skills, caregivers still try to handle instrumental (information, medical services), tangible (house work) and medical (administering medication) needs. Information about programs and support for caregivers is not easily reachable. Websites of cancer care centers generally give links to American Cancer Society and National Cancer Institute. But the amount of information is generally inadequate and not detailed to particular requirements of caregivers and family members (Given, Given & Sherwood, 2012). Yet still, to reach adequate information, internet is frequently used by patients and their caregivers.

Australia makes some suggestion on its governmental health page on their official website about living with cancer. Due to "getting back to normal" after surgery can take time, government website recommends patients to stay away from lifting things and weighty housework (Health Direct Australia, 2014). Furthermore, they are advised not to drive. In the long-term complications, this website warns about pain and hardness in patients' arms and shoulder in addition to other symptoms causing by early menopause including hot flushes, vaginal dryness and loss of sexual desire. After their treatment process, health system invites survivors for customary check-ups. Because of hair loss and other kinds of problems rooted in the way patient look during and after their treatment, there is a workshop called Look Good Feel Better. This workshop is free of charge and provides guidelines and counsel about dealing with this transformation. Yet, these workshops are available only in capital cities, not every region. Additionally, in program of Aids/Appliances for Disabled People, wigs might be provided for women who are suffering hair loss from chemotherapy according to their eligibility.

Apart from all these information, Australian government emphasizes on altered emotional characteristics of women which might create some changes in their familial relationships. For instance, it is advised to speak to a counselor or a sex therapist for patients who have problem in their sexual lives and are not getting better with time. Although government's approach is inclusive and wide-ranging on this topic, suggestions still stay in abstract level and do not turn into active steps. Moreover, the cost of cancer treatments shows variety according to the included insurance system (public or private), whether the patient continued to work or not, and the rate of travel costs. Local Medicare offices in Australia give personal information about the safety net on costs of the treatment. Also, the government-funded scheme is partially responsible for the costs of accommodation and travel.

During cancer treatment, day to day tasks can become difficult. According to a study in Australia, the most frequent supportive care needs of women with breast cancer are seen in their physical and daily living because they are not able to do things that they used to do (McDowell, Occhipinti, Ferguson, Dunn & Chambers, 2010). To overcome this obscurity, Australian government has regulated some practical support services. As a salient example, Meals on Wheels is a program which delivers meals on weekdays to houses for a minimal payment as a result of a recommendation from the doctor. And the other service is called domiciliary care services, which supplies basic domestic help and personal care. The cost of this service is attuned according to means-testing approach.

These regulations show the person-centered approach of the Australian government during treatment process. Yet these services are not universal and also they are given in return of a payment. This still demonstrates insufficiency of this approach.

Similar to Australian example, Canada has recently shown an approach to care issues with more person-centered perspective. Canadian government aspires to deliver care stem from individual needs, ethics and priorities. In order to reach patient satisfaction, they operate several quality control measurements, such as Edmonton Symptom Assessment System, Ontario Cancer Plan and Ambulatory Oncology Patient Satisfaction Survey (Canadian Partnership Against Cancer, 2014). These measurements generally focus on health related symptoms like tiredness, anxiety, depression, well-being and shortness of breath. Although Canadians do not pay out of pocket expenses for doctor visits and surgical and supportive treatments as a result of publicly provided health care, almost half of the expenditure was related with the managing with side effects of chemotherapy (Lauzier et al., 2013). However, Canada does not have a national health insurance plan. It mostly applies regional fund plans with private insurance plans (Aggarwal, Ginsburg & Fojo, 2014).

Besides these medical and supportive care plans, working lives of women with cancer were intended to be protected by legal regulations in these countries. The main perspective in this approach is the idea that cancer is a phase which renders patient vulnerable and fatigue, and during this process employees should not discriminate against them due to their side effects. For example, in Australia work lives of women with breast cancer are highly protected by legal regulations. Employers are forbidden to differentiate against the patient and rendered responsible for making some adjustments such as allowing time off, flexibility with working hours and tasks.

Similarly, in USA, The Family and Medical Leave Act of 1993 ensure patients to take reasonable unpaid leave for certain medical reasons. Not only women with breast cancer but also caregiver of a family member can benefit from this regulation. Employers are required to keep group health coverages of while their workers with cancer are on leave. As discussed earlier, Medicare is for elder people and Medicaid is designed for the deprived and those who cannot access to private health insurance plans. Thus, the rest of the society who are not eligible for these government-funded insurances is in hands of employer funded and employer facilitated healthcare plans (Spivak, 2014). The hidden catch in USA health system is that most of the insurance schemes introduced by the employers can be inactivated if the patient stops working. A study conducted in USA in this issue, analyzed attitudes of women who worked for employers sponsoring their health plans, thus cessation of working means a risk of losing their benefits. Results show that most women continued to work during their treatment, nonetheless chemotherapy recipients are found more expected to choose to end working (Hassett, O'Malley & Keating, 2009). Similarly, another study reveals that the rate of return to work of breast cancer survivors is highest in United States with 93%, while Netherland shows the lowest rate in world with 43% (Ilam, Dahlui, Majid, Nahar, Taib & Su, 2014). This divergence depictures the impact of health insurance systems and benefits on return to work rates of cancer survivors, both positively and negatively. In other words, in countries with no national health insurance systems, the fear of losing health insurance can considerably influence the conclusion of working or not. Benefits compensated to an employee who is absent from work is highly provided in most of the European countries in the case of treatment for cancer, but the United States is the only country that has no guaranteed paid sick leave.

There are multifarious factors behind the conclusion of not continue working. As mentioned earlier, health insurance system and benefits play the major role in this end. For example, according to a research conducted in Canada, wage loss due to cancer treatment process is one of the most significant adverse outcomes of this sickness (Lauzier et al., 2008). This study shows that wage lost is commonly associated with distance of living arrangements of patients to health care center, lower level of social support, chemotherapy and government employment insurance (Lauzier et al., 2008). Another reason of wage lost is the socioeconomic position and ethnicity of the cancer patient. Breast cancer’s non-employment effect appears to be twice as much as large for African American women compared with rest of the society (Bradley, Neumark, Bednarek & Schenk, 2005).

Not only cancer patients, but also caregivers are at risk of losing their works during the treatment process. In a study conducted in Canada shows that caregivers face augmented inability to work in ordinary hours due to their increased responsibility in the care they provided (Grunfeld et al., 2004). They usually try to use special leave and holidays to compensate these needs. Likewise, as can be seen in the perceived burden, majority of caregivers are endured to some psychological disorders such as anxiety and depression. And these psychological problems play a huge role in their professional lives.

3. 2. 2. High Human Development

Within the high Human Development Index areas, female breast cancer shows similar patterns in terms of their new cases per year (Bray, Jemal, Grey, Ferlay & Forman, 2012). Although higher HDI countries have generally higher public health expenditure and relatively more inclusive health and social policies, cancer is still one of the most common causes of death, and the breast cancer is the most common one for women. Malaysia, Iran and Brazil are three examples for high development index countries. Similarly, Turkey is ranked among this group and it will be discussed in the next chapter in depth.

These countries with high development scores have their own national health insurance schemes, with different coverage conditions and practices. Yet there is still a dilemma in their coverage and eligibility criteria. For example, in Brazil, cancer patients can qualify for several benefits, such as sickness pay and disability retirement. However, these benefits do not cover all citizens. (Gravena et al., 2013). Actually, Brazil health insurance scheme has strict eligibility criteria on deciding who will benefit from sickness pay and disability retirement. The coverage may be result of differences in approaches of these countries to welfare state as an idea. If they have a broader understanding in terms of responsibilities which a government should have, they provide broader services for more coverage in terms of population. Additionally, resources of countries also affect the capabilities to provide such benefits.

Disparities based on resource of countries show its impact rigorously in Iran. The average age of breast cancer is earlier than developed countries because of shorter life expectancy (Mousavi et al., 2007). Although Iran government employs healthcare workforces and equipment, it is problematic to implement a unique cancer strategy due to cultural, religious and social differences (Asadzadeh, Broeders, Kiemeney & Verbeek, 2011). Thus it is possible to argue that, economic resources, as well as cultural, religious and social differences play a major role in approaches of countries to welfare state and health and social policy practices, especially in their government-funded health services.

Another picture showing the huge impact of cultural, religious and social factors on cancer incidents can be seen in another high development index country, namely Malaysia. In Malaysia, beliefs in complementary alternative medicine and fear of cancer consequences render psychological counseling necessary for all cancer patients. These psychological factors play a chief role in the conclusion that a quarter of the cancer incidents can be diagnosed in their third stage of cancer and 18% of the incidents can be found even after the fourth stage of the illness (Norsa'adah, Rahmah, Rampal & Knight, 2012). Late diagnosis directly and negatively reflects on the chance of survival of patients. Both patients and their families cannot reach adequate counseling, thus they embitter the fear in the society. Additionally there is a lack in a policy of campaign for raising the awareness for cancer in public. To sum up, although these countries are highly ranked countries in Human Development Index 2015, they mostly lack inclusive and universal health and social policies to enhance the quality of life and care of women with breast cancer and their caregivers.

3. 2. 3. Medium Human Development

Generally, in medium-resource areas there is a gap in high quality cancer care due to a shortage in population-based cancer registries, inclusive policies and increased incidence rates of female breast cancer (Bray, Jemal, Grey, Ferlay & Forman, 2012). Although it is not possible to analyze medium human development countries just by examining four countries, examples from South Africa, India, Ghana and Bangladesh will try to represent general framework of this group.

Firstly, Cancer Control Plans, seen in almost all very high developed countries, are also seen in some countries in this group. Surprisingly, in South Africa, South Africa Cancer Control Plan was planned in 1993. However, it was only after 1999, the National Department of Health adopted it and put some recommendations into practice (Cristina, 2015). One of the most important implications provided by this control plan was the regular screenings. South Africa has started to offer free cancer screenings for 5 major types of cancer. Yet, there remains a question whether this practice is effective due to the long time intervals (Jung, 2015). Indeed, the longtime intervals between expected cancer screenings are mainly rooted in shortage in medical equipment and specialists.

The shortage in medical equipment and human resources may have vital consequences in terms of both treatment and stages of diagnosis. For instance, India also lacks adequate screening options. As a result of this deficiency, 61% of women with breast cancer were diagnosed at the stage four in Delhi (Pakseresht, Ingle, Garg & Sarafraz, 2014). This can be mainly because of the ineffective screening policies and lack of screening machines. The same study reveals that women with lower income are more likely to be diagnosed at advanced stages of breast cancer. Therefore, these countries should immediately develop effective and well-designed screening services covering all population.

In a similar manner, Bangladesh has a deficiency of radiation therapy machines, hospital bed, trained oncologists and technologists (Hussain & Sullivan, 2013). Although, there is a need for 300 radiotherapy centers to meet the demand, the country has only 17 centers, only one of which located in rural area of the country. This inequality creates negative consequences, because in rural areas the costs of travel to the nearest hospital cannot be affordable for every family (Ginsburg, 2013). On the other hand, in Bangladesh, majority of the total spending on health is funded through out of pocket payments. In other words, there is not any well-structured government-funded insurance system providing cancer treatment. Therefore, one can safely argue that countries with middle Human Development Scores have severe shortages in their infrastructure and human resources. This adversely affects the quality of lives and cares of their citizens.

3. 2. 4. Low Human Development

Major challenges in front of a high quality cancer care in low-income countries are financial constraints, lack of scientific information, a shortage of professionals, political insecurity and social/cultural factors (Anderson et al., 2006). Moreover, economic impact of cancer is perceived diagnosis only in advanced stages of cancer, because these low-resource countries have variety of priorities besides to cancer treatment. In other words, in low HDI regions, breast cancer is one of the most widespread cancer types in women, but two further infection-related cancers, namely cervical cancer and Kaposi sarcoma are also common (Bray, Jemal, Grey, Ferlay & Forman, 2012). Thus, the priority is generally given to these cancer types and other infection-related illnesses.

Majority of the low and middle income countries suffers from an insufficient insurance for their citizens (Bridges et al., 2011). Thus, although countries have a theoretical framework regarding cancer care, they face some difficulties in implementing those regulations. Women face obstacles in all stages of the necessary care for breast cancer in lower human development index regions, but most frequently in the treatment period (Gonçalves, Travassos, Almeida, Guimaraes & Gois, 2014). In resource-limited countries, medical treatment is not provided in sufficient amounts. Take Tanzania as an example, which employed only one medical oncologist, four radiation oncologists and two physicists for its total population (Eguzo & Camazine, 2012). Therefore, these countries cannot provide the necessary treatment to their citizens.

Women with breast cancer living in rural regions experience double burden of cancer in countries with insufficient medical professionals. There can be two main reasons of it. Firstly, expenses of treatment can be really high and it is not always possible to afford them. And second, cancer patients and caregivers should also try to overcome the transportation and distance difficulties to their treatment. Due to the unequal ratio of medical experts to population, most of the people have difficulties in access to diagnosis and treatment. Furthermore, national insurance systems do no generally include all cost of cancer treatment. For instance, Nigeria and Ghana has excluded cancer treatment from their National Health Insurance Schemes (Odeyemi & Nixon, 2013).

Universal disproportions in breast cancer control endure due to a lack of a widespread control strategy in many countries. Perhaps, one of the most important indicators of a compassionate health system is national registration arrangement within a well-designed national cancer strategy. It provides nearly all necessary characteristics of health graphics of populations. However, there is a mutually reinforcing relation between a well-constructed registry system and an inclusive health insurance. A lack of population-based data on cancer indicates the underappreciated point of view to this issue. Thus, a myriad of low-income countries does not have an efficient health recording system and as a result of this lack, screening is not generally applied (Akinyemiju, 2012). As a result of some forms of barriers any lack in screening programs. These barriers can be grouped as difficulties in access to health systems, insufficient information, problems in infrastructure and socioeconomic conditions. For instance, population-based registration system does not exist in Kenya. And this paucity directly reflects to ratios of cancer survivors to all cancer patients. In other words, in these countries, mortality due to cancer is really high (Ferlay et al., 2014). Due to lack of advanced medical opportunities, low awareness and inadequate screening services, 80% of cancer patients diagnosed at their advanced stages and quite few of them can achieve the curative treatment because of distant referral and delays (Republic of Kenya Ministry of Public Health and Sanitation and Ministry of Medical Services, 2011). Perhaps, Kenya is one of the most striking examples showing the crucial impact of institutional barriers on women with breast cancer, as can be seen in this example. Therefore, low-resource countries should immediately solve their infrastructure-related deficiencies to increase the quality of life and care of their citizens.

CHAPTER IV

HEALTH SYSTEM IN TURKEY

4. 1. Health System in Turkey before the Health Transformation Program

Actually, welfare state is a relatively new concept for Turkey. It is started to be used only after 1960s. The Socialization of Health Services Delivery Act of 1961 was the first regulation which touches upon that wellbeing of citizens and medical care are natural rights which should be fulfilled by the state policy (Yavuz, 2011). Having been stated in this written regulation, provision of health services to each member of the residents was aimed to be conducted on the basis of equity and priority. This regulation has a prominent importance for being the first written text in which Turkey renders itself a social state. Although Turkey has named itself as a social state, its actions were not fully generated in this principle. For instance, during this era, health system in Turkey was mainly financed through general taxation with some user charges. Although in the Constitution, Turkish State has defined itself as a social state since 1961, until recently there was no well-defined and developed health policy which is expected to be more inclusive and universal (Ersoy & Sarp, 1998).

During the last 30 years, Turkey has encountered with massive urbanization, rapid industrialization, changes in population and increasing chronic diseases, resulting in the augmentation in health spending (Mandıracıoğlu, 2010). These alterations evoked a necessity to plan the health system of Turkey, in the similar vein with other developing countries. Turkish welfare regime has undergone a salient transformation since the 1980s (Buğra & Keyder, 2006). First, with the introduction of neoliberal policies by military regime of 1980 and following civilian new right governments, the role of the state in economy, thus welfare mix, have been fundamentally changed (Buğra & Adar, 2008). Second, periodic economic crises since 1980s and massive rural to urban migration have led to the erosion of family and kinship based solidarity. In parallel to these transformations, some structural adjustments and market-oriented reforms were implemented. For instance, the Constitution of 1982 changed the fundamental duty of government from provision to regulation of the public health services (Davas, 2011).

In the years following 1980s, public policy was influenced by neo-liberal discourses. The standpoint of the new ruling government was contradicted with the health policy of that era (Kılıç, 2008). During the same period, some policy changes were conducted to enhance privatization in health service provision, such as giving permission to medical doctors working at public amenities to open their own private clinics and beginning of copayments for various drugs (Yaşar, 2011). The Fundamental Law of Health Services of 1987 aimed to change the centralist organization of public hospitals by increased decentralization (Altan, Kerman & Eke, 2013). Nonetheless, none of these purposes could have successfully been implied. After a decade, 1990s has passed with abstract national health programs that cannot leave the paper and meet the real world, such as decentralization in health management system and family medicine scheme. The solid change of that decade was the introduction of Green Card in 1992 to make health care possible for people who cannot compensate its cost. Green Card as a means tested health care assistance scheme regulated by General Directorate of Social Assistance and Solidarity (Yoltar, 2009). Other plans and programs could only turn into concrete legal regulations in 2000s as a part of Health Transformation Program.

To summarize, before the Health Transformation Reform, Turkey had highly polarized, fragmented and hierarchical formal social security system. It included three institutions based on occupational groups (Boratav, Yeldan, & Köse, 2000). The first is the Social Security Institution for workers in formal sector (Sosyal Sigortalar Kurumu – SSK) founded in 1945. The Retirement Chest (Emekli Sandığı) for civil servants was the second institution founded in 1949. The third institution was founded in 1971, namely the Social Security Institution for the Self-employed (Esnaf, Sanatkarlar ve Diğer Bağımsız Çalışanlar Sosyal Sigortalar Kurumu - BAĞ-KUR). All these institutions provided health and pension provisions for beneficiaries and their dependents with different norms and standards (Kocacık, 2001). But this system of social security left unprotected almost half of the population without social security insurance. In other words, this system only protected formal sector workers. It left formally unprotected unpaid family labor and informal employment which historically constitutes majority of the work force in Turkey (Buğra & Keyder, 2006). Turkish Health System is structured in such a way that, without any insurance, people are deprived of the means to obtain proper health care and pension. Since 1976, the retirement chest has provided monthly pension to elderly above the age of 65 and disabled above the age of 18. As will be discussed below, these three institutions were united under a single umbrella institution in 2008 with Social Security Institution Law (Elveren, 2008).

4. 2. Health Transformation Program

During the last three decades, almost every country has tried to implement a transformation to their social security system, and most particularly to their health system. Actually, despite their economic and social differences, a myriad of countries from Asia, Europe, Latin America and Africa has been conversing on similar changes about their health policies. The chief reason of this is rooted in the neoliberal dynamics which have penetrated into the economic and political structures of these countries (Günaydın, 2011). In fact, the purpose of this transformation is in parallel with neoliberal discourses, which can be summarized by decrease in expenses and increase in efficiency without any limitation in access of the society to health care. Similarly, the health transformation of Turkey is put into practice in 2003; however, it actually is the result of neoliberal structural transformation programs adopted since 1980s (Şahin, Özcan & Özgen, 2009). The Constitution of 1982 has performed fundamental amendments in the role of government in health by degrading it to supervisor and monitoring position. Another noteworthiness of this constitution lies in its emphasis on general health insurance and co-payment. The same period brought different means for legitimation of health transformation such as ethical violations of medical doctors and other difficulties generated as a result of structural deficiencies (Elbek & Adaş, 2009).

Before the health transformation, since the beginnings of 1990s, social security system faced serious financial predicaments with the risk of blockage in Turkey (Gümüş, 2010). Thus, Ministry of Health took European countries as its role models for this program; nonetheless, Turkey is utterly dissimilar with them in terms of its social policies, organizational structure, financial situation and human resources (Özdemir, Ocaktan & Akdur, 2003). Thus such a modeling is problematic from the beginning due to these fundamental differences. The Health Transformation Program should be understood in the light of these motives and historical background since 1980s. In other words, Health Transformation of Turkey should be analyzed within its own unique historical and structural particularity.

Health Transformation Program can be taken as a two-staged process. The first period, between 2003 and 2009 was a project aiming the basic transformation in health system in Turkey. And the second phase was between 2009 and 2014 included social security reforms to its package. Efficiency, productivity and equality are the concepts providing a road map for health transformation program in organizing, financing and delivering health services (Başol & Işık, 2015). This program has nine main principles as divided by the Turkish Ministry of Health, namely human centrism, sustainability, continuous quality improvement, participation, reconcilement, volunteerism, division of power, decentralization and competition in service (TC Sağlık Bakanlığı, 2007). Although Ministry of Health constructs 9 subheadings to show the main principles and aims of the Health Transformation Program, they can be grouped under four main groups. Components of health transformation program can be summarized as follows.

Firstly, The Ministry of Health has become the planner and controller of health services, instead of providing them. Throughout this transformation, the duty of Ministry of Health has been shifted to include policy generating, controlling and monitoring practices

(Dündar, Uzak & Karabulut, 2010). From then on, Ministry of Health is not the provider of health services, but the purchaser of service from private health institutions. For this purpose, chief amendments were implied on the structure of central and provincial organizations by rising responsibilities of the latter ones. This new instruction fashioned a Ministry of Health which is a manager and a conspirator, rather than a service supplier.

Moreover, Health Transformation Program has issued a General Health Insurance. As discussed earlier, social security system had had a segmented characteristic, including Social Insurance Institution, Social Security Organization for Self-Employed and Social Security Organization for Civil Servants before the new umbrella approach introduced. In the old form both services and coverage were not provided with a standardized consistency. Moreover, the majority of population was not included in the insurance protection, some of which was entitled to Green Card (Karadeniz, 2012). Health Transformation Program tried to eliminate these inequalities in health services among three social security institutions. However, General Health Insurance has been prevented from reaching width coverage due to informal economy, high unemployment rate, unequal income distribution and widespread poverty (Yaşar & Uğurluoğlu, 2011). The urgent need of a mandatory health insurance system covering all members of society to improve the quality of services and bypassing the disparity among the citizens was tried to be handled by eliminating the financial relation between the patient and doctor. Hospitals managed by Ministry of Health were rendered free to access of private sector insurers.

The separation of health insurance from the present social security institutions and collecting all health insurance system under a single umbrella was the main condition of this regulation. For this purpose, some steps were introduced to take citizens under guarantee such as the definition of level of poverty, provision of public resources to partially refund the eligible people, separation of health premium pool from other social security subsystems, introduction of main guarantee package in the health services and establishment of contracts to purchase service from primary health institutions (Gökbayrak, 2010). Most importantly, a National Health Budget has been set up to pursue the mobilization of resource capacity. All these steps were taken in accordance with the Ministry of Labor and Social Security. General Health Insurance constitutes from different components, the first of which premiums shared by employer and employee. In this share government’s premium is only 3% (TC Sağlık Bakanlığı, 2007). Additionally, the second financial resource of this insurance scheme is the co-payments paid by insurance holders.

Thirdly, this transformation program has brought Primary Health Care Services and Family Medicine into the context of Turkey. Developing a well-established primary health care system was one of the most dominant aim of the Health Transformation Program. Correlatively, with the neo-liberal discourse, individuals were encouraged to choose their own family physicians. More importantly, this program has taken the individuals as a group with their families by considering the idea that health is produced within a family environment (Yavuz, 2011). Thus, the primary health care service was in hands of family practitioners.

Current, general physicians should participate in internal training program lasts for ten days started to be given by the Ministry of Health. This education was the only way to become family physicians (Öztek, 2006). Family physicians are responsible for the health of all household members. These doctors are paid a monthly capitation imbursement according to the number of people registered to them. It was planned that empowerment of primary health care would decrease the burden of overcrowded hospitals and excessive health expenses (Ergun & Ergun, 2010). However, family physicians would be the main responsible for staged referral chain. In other words, after the registration and treatment of each patient, they decide the next step of following chain including secondary and third level institutions. If this referral chain is not followed by the patient, s/he must pay a co-payment in the case of applying hospital directly. Although the Ministry of Health has been eager to structure a proper referral chain, it still defines breaking of this chain by a patient as a right. Since 2007, primary care services have been free even for the people who are not within the scope of any health insurance (OECD and World Bank, 2008). The new regulation of emancipating the use of both private and public hospitals can be read as a conspicuous approach expanding the convenient facility effectively in health services. Additionally, basic health services were expanded drastically during the Health Transformation Program. Ambulance service of the public institutions is promised to be provided free of charge (Başol & Işık, 2015). Similarly, emergency health care services were excluded from the payment chain. In other words, patients are not subjected to any out of pocket expenses in case of emergency. And lastly, conditional cash transfers started to be disbursed to encourage mothers to have regular check-ups for their children.

And the last renovation brought by this program is the financial and administrative authority of health enterprises. Each hospital, including private ones, can provide services to citizens as long as they make necessary arrangements with insurance institutions and pay importance to the referral chain (Erençin & Yolcu, 2008). Upon necessary controls about the prices, those hospitals can provide services. One of the main intentions behind this directive is to increase effectiveness in public hospitals. Similarly, each public hospital has also gained autonomy under the control of the Ministry of Health, thus they became responsible for their own organizational decisions, service quality and finance (Saraçoğlu, Sülkü & Açıkgöz, 2012)

Despite these well-established aims, one cannot always be sure what causes something, nor can one predict with certainty what effects may result. The traditional views of the governments about health system in Turkey are so deeply ingrained that they have not really changed (Kurt & Şasmaz, 2012). The success of health reforms can be understood only according to the changes they produced on the society, rather than the intentions and motives of the governments (Browne, Roberts, Gafni, Byrne, Kertyzia & Loney, 2004). By analyzing the impact of health transformation program on the current health services, one can easily reach the conclusion that the ultimate goals have not been reached during this period.

To summarize the health system after the transformation, one can argue that this system brings new striking regulations health care practices. Maybe the most important was that family practitioners have payment based on performance (Akman, 2014). This means that they are paid per patient they have been applied. In other words, the more patient registered to them, the more payment they gained. This system of payment encourages family practitioners to register patients as much as they can reach, which means the decrease in time allocated per patient. More important than this, there is a structural transformation in the relationship between patient and physician. Indeed, many scholars argued that it has turned into consultant customer relationship because some family practitioners are inclined to give importance to their number of registration instead of treatment process (Uğurlu, Eğici, Yıldırım, Örnek & Üstü, 2012).

Although one of the most important aspects of this program is the empowerment of primary care services, there are no meaningful improvements in primary care. It still lacks central provisions such as sponginess number and quality workforce, unbalanced distribution patients per family practitioners and lack of applications supporting multidisciplinary approach (Akman, 2014). In public health expenses, government’s main priority is on preventive and primary health care rather than curative and medical care. The underlying motive behind this decision might be the fact that benefit of the first one is higher than its cost in terms of the allotment of public resources (Yazıhan & Yılmaz, 2015). In other words, cost of treatment would be decreased by treating cancer in its earlier stages.

All in all, General Health Insurance system remains far from providing coverage of the entire population because access to health insurance is mainly based on payment of premiums. A matter of considerable controversy at present is the issue of whether Health Transformation Program has ended the disparity among the citizens in terms of access to health services or rather expanded it by giving more rights to people who are able to pay their premiums. In other words, Health Transformation Program is a controversial issue whether it created a new inequality based on income or expanded the accessibility of health services for lower income group of people. According to a study analyzing the service satisfaction in health system has revealed that contentedness is increased in the lowest 30% income group relatively more than that in the highest 70% income group people apart from their insurance situation (Hazama, 2015). Additionally, insurance coverage for the lowest income group supplied by the government has increased dramatically that 2,4 million people in 2003 have rose to 10.2 million in 2011 (Atun et al., 2013). Therefore, although the Health Transformation Program has brought huge renovations to the current health system of Turkey, it still needs more regulations to provide high quality of care.

4. 3. Cancer Control in Turkey

In Turkey, breast cancer is ranked among the most fatal diseases, as noted above. Still, breast cancer is a type of disease with longer life expectancy and the best prognosis. Thus, living with cancer is longer in breast cancer. Under these circumstances, health and social policies have become vital to increase the quality of life for women with breast cancer, caregivers and other family members. Nevertheless, Turkey has shown inefficient activity in the fight against cancer. In this part, the history of health arrangements regarding breast cancer will be examined.

The fight against cancer does not have a long history in Turkey. Not until the Turkish Association for Cancer Research and Control was founded in 1947, functioning as a civil initiative on this particular subject, public awareness was not raised and treatment procedures were not shaped (Ministry of Health, 2011). However, until 1960s, cancer treatment was fulfilled by general hospitals, not specialized in the oncology field. In 1960s two oncology hospitals were established in the capital city of Turkey, Ankara (Ministry of Health, 2009). During the same decade, as the first official movement to fight against cancer, government set up a branch which turned into a directorate in 1970 (Ministry of Health, 2009). After 20 years, Turkey became a member of the International Union against Cancer to share experiences and establish partnerships on this topic.

Perhaps, the most important point in the fight against cancer is the systematic and national data registry, because it is not possible to decide on which type of cancer has more importance than the other types of cancers and direct human resources and infrastructure to the right channel in making strategic plans. Within this framework, in 1982 cancer was taken into the scope of “reportable diseases”, but the method used in recording was a passive approach (Aydın, 2007). Therefore, the incidences of mortality in incommunicable diseases were not recorded properly until 2008, and the reasons behind deaths were registered only in big city centers. It was only after 2009 registration of mortality were tried to be rendered formal and systematic (Ministry of Health, 2011). For this purpose, in the cities in which active cancer registry centers are located there are multiple steps in cancer registry such as collection of data from public, private and educational hospitals and nursing houses. However, due to the lack of data density and lack of data centers in most centers, incidences of cancer mortality are still shadowy (Tuncer, 2009). But still, it can be said that one of each four women cancer is breast cancer in Turkey (Gültekin & Boztaş, 2014).

In addition to the lack of proper records, lack of early diagnosis is another deficiency in cancer care in Turkey. Breast cancer is a progressive disease. In the early phase of diagnosis the possibility of successful treatment is higher, which makes life expectancy also higher. Thus, Turkish national health regulations prescribe screening for women aged between 40 and 69 in every two years. Cancer screenings in Turkey are handled by Cancer Early Diagnosis Screening and Training Centers (Kanser Erken Teşhis Tarama ve Eğitim Merkezleri / KETEM). There are 134 KETEMs in Turkey, at least one for each city (Ministry of Health, 2014). Since 2008, KETEMs have been providing free cancer screening for women. Women aged 40 to 69 can be scanned in every 2 years according to National Cancer Control Program (Tuncer, 2009). Nevertheless, breast cancer screening is still limited to a small proportion of female citizens; which is much lower than the aimed. This deficiency is due to three underlying reasons, such as inadequate human resources, lack of awareness and problems in the availability of services (Özmen, 2013). As a salient example, the number of radiologists is so few that it is not possible for them to assess the radiological results properly and efficiently. Under these conditions, according to the available data, most of the breast cancer incidences in Turkey are detected at their third or fourth phases (Özmen, 2013). Consequently, there is an urgent need for national screening programs which include most of the population. Therefore, cancer registration and screening implementations in Turkey are not sufficient under the current circumstances.

Further, cancer centers are not sufficient considering needs of Turkey. In addition to this deficiency, these cancer care units are not work in a harmony with each other. In other words, there is no coordination among these institutions in terms of division of labor and cooperation. Radiation oncology centers, one of the most imperative components of cancer treatment, is both limited and unequally distributed among regions (Kuter & Çakır, 2004). More importantly most of them do not have adequate technological equipment (Erkoç & Yardım, 2011). Additionally, big hospitals specialized in cancer treatment with their experienced staff are located in big cities. Thus, one can safely argue that patients are obliged to move to these cities for medical opportunities during their cancer treatment. Still, cancer diagnosis and treatment has gained importance within the establishment of health transformation program. According to the regulation accepted in 2010, cancer patients are not obliged to make any payment during their radiotherapy and chemotherapy (Başol & Işık, 2015). This regulation has made it easier for patients to reach the basic treatment and care. However, there is still a significant gap in legal regulations in terms of patient and caregiver rights. Similarly, current health system has significant lacks and deficiencies in terms of cancer.

Cancer care in Turkey is provided considering only the current basic necessities. One of the principal reasons of this is the inefficient human resources. Unfortunately, cancer care system in Turkey employs only one to third of the required professionals. To be more precise, when examining the present situation, there are 175 medical oncologists, 97 pediatric oncologists, 306 radiation oncologists, 88 radiation physicists, 525 oncology nurses, 50 psychologists and 23 social service specialists (Sağlık Bakanlığı ve Temel Sağlık Hizmetleri Genel Müdürlüğü, 2011). According to a recent study, 81,7% of cancer patients are in need of rehabilitation and 24% of them cannot perform their daily activities (Aras, Delialioğlu, Atalay & Taflan-Selçuk, 2009). These results highlight the inadequacy of human resources, not only in terms of medical care but also in psychology and social domains of cancer care.

More dolorously, among European countries the last country in terms of number of medical oncologist per patient is Turkey. There are only 2,4 specialists for one million people in need of cancer care (Türkiye Büyük Millet Meclisi, 2010). For instance, 52% of the total cancer patients are in need of one cure, 25% of them two cures of radiotherapies. Thus, the capacity of radiology specialists should urgently be increased. Moreover, in breast cancer screening, radiologists, who are necessary to review the results of scanning, are not in sufficient by number (TBMM, 2010). As mentioned earlier, in Health Transformation Program, family practitioners have gained importance. However, oncology education is not included efficiently to their rotation training program. Thus, the main responsible in the primary care service is not proficient for cancer care.

Turkey lacks a multidisciplinary approach in cancer care which is an essential part of a high quality treatment. Each cancer patient has a different type of cancer due to the differences in stage, type and place of tumors. In multidisciplinary approach, each patient has its own path for treatment with specialists from different fields. However, in Turkey even medical surgery for breast cancer is handled by general surgerists. In such a compact and mixed operation, experts with no special experiences in breast biology could not be responsible on their own (Türkiye Büyük Millet Meclisi, 2010). This shows that it must be a sub-branch of breast oncology in both education and practice. Under these conditions, in many cases inefficient surgeries would lead further surgeries in following phases.

For most of the countries, one of the most essential predicaments is to allocate obligatory resources for cancer treatment. A high quality cancer care requires a high technology in devices and equipment. Currently, Turkey cannot produce the compulsory appurtenances such as radiology screening machines within its borders. Thus cancer care is dependent on exportation (Türkiye Bilimler Akademisi, 2014). However, Turkey needs high-technology machines to provide the basic treatment. Machines and necessary drugs used in chemotherapy and radiotherapy create a huge economic burden on Turkey. For instance, radiotherapy machines are especially expensive (Jakivijevic, Zugic, Rankovic & Dagovic, 2015). However, in lower income countries, radiotherapy has a more vital importance due to the late diagnosis and characteristics of most spread cancer types. Moreover, due to the small number of machines, they can be broken down easily. Patients can wait for weeks to reach the appropriate equipment for their treatments due to long maintenance and repair span. More importantly, countries can also create unequal distribution of necessary equipment. This means treatment machines can show regional differences in the same country. For instance, medical imaging devices can be adequate in terms of their numbers for a country. Yet, they can be distributed without considering the regional needs and demographical disproportions. Actually, Turkey can be a good example for this. In Turkey, in some regions patients face difficulties in access to necessary treatment due to lack of appropriate devices (Güler & Güllüoğlu, 2014).

Besides deficiencies in the necessary infrastructure in terms of equipment, devices and human resources, health and social policies also have fundamental lacks. For instance, end of life care policies is not well-developed and well-established in Turkey. According to WHO, palliative care should be taken into consideration as an integrated approach involving solutions for physical and psychosocial problems faced by both patients and their families (Ventafridda, 2006). However, in the health system of Turkey, the significance of palliative care has not been understood. Patients in their terminal periods are generally cared and supported by their families and relatives in houses as a result of traditional family-kinship solidarity dynamics. Actually, most of the hospitals in England, Canada and United States have specialized palliative care units in oncology hospitals (Feudtner, Womer, Augustin, Remke, Wolfe, Friebert & Weissman, 2013). However, in Turkey there were no palliative care units until recently (Başer, Kahveci, Döner & Özkara, 2014). The Ministry of Health has recently issued a regulation about palliative care units. And it is possible to expect gradual increase in the palliative care units and facilities.

Besides palliative care, health and social policies have some lacks in psychological, tangible and social care needs of women with breast cancer. Due to lack of efficient support mechanisms in place, care is generally undertaken by family members in Turkey. Neither social workers nor social nurses are employed in this field. However, cancer patients face certain difficulties in their domestic and social lives during cancer treatment process. Indeed, most patients need help in housework, cooking and cleaning, and some of them have troubles in their personal care during radiation treatment process (Ertem, Kalkım, Bulut & Sevil, 2009). More drastically, the same study proves that all need of them are tried to be handled by their family members. However, these needs cannot be solved professionally by these people who did not take any education within this specific field. Therefore, there is an urgent need for a holistic approach in health and social policies regarding cancer. In this approach, care needs of women with breast cancer should be provided by well-educated social workers.

Working life of patients and caregivers is another controversial issue. There are certain deficiencies in protective legislations for cancer patients and caregivers especially in informal sector. Actually, regulations have no strict enforcements on employers except for cancer is the result of work environment. In this regulation, there are several criteria. To be qualified for invalidity pension, the patient should have a work-induced cancer. Additionally, according to Social Security and General Health Insurance regulation, the cancer patient should also have ten years of insurance, five years of paid premium and 60% lost work labor. If a patient can prove her eligibility according to these criteria, then she deserves a right to invalidity pension (SGK, 2013). In other cases, work life of patients is left alone to judgment of employers. In some occasions, patient who is not able to continue her work life due to health conditions can be excluded from seniority indemnity, although it is one of the basic rights. Although General Health Insurance has aimed to eliminate the disparities between three insurer groups, patient rights still show variety between the work branches. As an outstanding example, civil servants can benefit from some special implementations during their treatment process. In other words, cancer patients can receive permission for 18 months, as long as their treatment last. On the other hand, same application reinforces care function of family. If a family member became cancer, civil servant can have permission for three months to take care of her/him.

One can also argue that transportation during the treatment process is another expense item for cancer patients. In some parts of the treatment, patients can be obliged to transfer to hospital every day. Public transportation may create a huge burden on cancer patient. However personal transportations, such as taxi or private cars cannot be always possible. Moreover, treatment devices are not equally distributed among regions. Thus, patients can change cities for chemotherapy or radio therapy. In these situations, payment for transportation can be impossible to handle for some patients. In some cases, where state benefits are inadequate, the ability to pay transportation to hospital can indeed become a matter of life and death. In Turkey, some health services are met by the government according to eligibility criteria. The same benefits are applicable for inter-city transportation too. According to the recent regulation introduced by Social Security Institution, if patients with breast cancer have gained right to health protection supplied by the government, then she can get the payment of their transportation as long as they handed the bill of it. But still, there is a myriad of conditions for this benefit such as day limit, referral chain and pre-determined transportations.

Therefore, it is possible to state that Turkey has some fundamental lacks in its health and social policies, regarding breast cancer care. Actually, the recent health transformation program introduced some improvements in cancer treatment. Still, women with breast cancer, caregivers and other family members have several needs unmet by the current health and social policies. Cancer diagnosis and treatment process have physical, psychological, economic and familial impacts on patients and caregivers. What is more, institutional regulations and practices are not effective and sufficient to provide the necessary care to diminish the physical, psychological, economic and familial impacts of breast cancer. In the following chapter, these impacts will be analyzed in depth.

CHAPTER V

BREAST CANCER AS A LIFE CHANGING EVENT

We all wish we knew what life will bring to us and what is waiting for us around the corner. Unfortunately, life provides different experiences without a clue or warning, and circumstances change. People, at all ages, face with different circumstances like a life-changing illness which creates a need for long term care. We all have thought how it would be that being an individual needing such a care or being responsible for care needs of another individual. We keep asking questions like when and where we can provide or take help, what and how should be “the help”, will we be able to afford it, how we can choose the right path to follow… etc. These questions are vital for individuals and families facing these challenging circumstances.

One can argue that cancer is one of the most common life-changing events. It comes without a warning and incurs long-term needs. Actually, in the cancer treatment process, there are several needs unmet by the medical institutions and uncovered in legal regulations. In the absence of support systems in place, patients try to overcome these difficulties and strains with their families, if there is a willing caregiver (Nijboer et. al., 1998). Otherwise, women with breast cancer try to handle all troubles by themselves. However, cancer care is much harder than other types of care undertaken by family. Indeed, it necessitates a huge physical effort. In most cases, the duration of cancer care can be very long and unpredictable. And this type of care requires a specific knowledge and expertise. Thus, cancer treatment process evokes new needs for cancer patients and families in terms of quality of life and care. Although quality of life of patients and other family members have been neglected (Hacıalioğlu el. al., 2010), the impact of breast cancer from the perspective of the family caregivers also needs attention. There are different types of caregivers based on care-giving involvement and care-giving outcomes.

Some caregivers are responsible for economic needs of patients, while some others provide physical support or emotional support.

Although in psychology literature there are scales that measure the needs of patients and family members (Bozo, Gündoğdu & Büyükaşık-Çolak, 2009), it is not easy to find out qualitative studies about the scale and scope of emerging needs throughout the treatment process in other social science fields. These needs may vary according to cultural, socio-economic, regional and many other variables. Thus, in order to understand the experiences, expectations and needs of women with breast cancer and caregivers, I will try to analyze impacts of the treatment process on their lives. For this purpose, in the following pages, impacts of cancer treatment process will be discussed under five headings. They are namely physical impact, psychological impact, economic impact, familial impact and institutional lacks. Under each heading, I will present analysis of the interviews with women with breast cancer, caregivers and experts.

5. 1. Living with Physical Impacts of Breast Cancer

Cancer diagnosis and treatment process produce intense physical effects on patients. Especially the treatment process of cancer leads to severe side effects on them. Fatigue throughout the active treatment and post-treatment process is one of the most common side effects seen in patients with cancer (Knobf, 1986). Indeed, fatigue is the most distressful physical symptom and causes decrease in quality of life (Byar, Berger, Bakken & Cetak, 2006). Sleep disturbances and pain are also among the most common, severe and distressing physical symptoms (Beck, Dudley & Barsevick, 2005). Additionally, as a side effect of chemo/radiotherapy, most cancer patients face taste and smell changes (Steinbach, et al., 2009). Cancer patients, in general, are worried about their appearance, weight, and body (McGarvey, Baum, Pinkerton & Rogers, 2001). For instance, they have been experiencing adverse effects of chemotherapy-induced alopecia (hair loss). Indeed, hair loss is ranked as the most challenging side effect during cancer treatment process (Lemieux, Mansell & Provencher, 2008).

In addition to these, breast cancer has its own unique physical effects. Due to the location of cancer-tumor, the removal of the axillary lymph nodes causes lymph edema in arms (Armer, 2009). Therefore, majority of breast cancer patients face symptoms of lymph edema (Paskett & Stark, 2000). This side effect aggravates upper-body movement during breast cancer treatment. Upper body strength troubles are particularly relevant to breast cancer patients. These kinds of physical side effects exacerbate everyday lives of patients. Especially they face difficulties in their daily life tasks such as preparing meals, housework and child care. Thus, these difficulties have also fundamental reflections on daily lives of family members of women with breast cancer.

According to Jones (2012), caregiver is defined as an individual assisting with health care activities for cancer patients who are unable to independently care for themselves or require aid to handle with their care related to cancer or cancer treatment. Thus, caregivers can be seen as an extension of the professional cancer human resources. In this thesis, caregiver is defined as a close individual emotionally involved with the patient and identified by the patient as her key source of emotional and physical support. It is not possible to define only one health proxy as a caregiver because care-giving is a multidimensional activity. Cancer care is multidimensional and shows variety between health care proxies. In the following pages, negative physical effects of diagnosis and treatment process on patients and caregivers will be examined.

5.1.1. Patients' Experiences with Physical Impacts of Breast Cancer

Breast cancer patients experience numerous side effects and treatment-related troubles. These difficulties in upper-body tasks deteriorate simple everyday responsibilities such as pain while driving and sleeping, posture disturbances, and declined skills to do housework and cooking (Collins, Nash, Round & Newman, 2004). In most assessment indices, physical functioning was reviewed through the level of difficulty in performing ten physical activities. They include pushing or pulling large objects, incline in body posture, lifting, reaching, standing, climbing upstairs, and walking (Vinokur, Threatt, Vinokur-

Kaplan & Satariano, 1990). Likewise, cancer treatment process has also severe adverse impacts on doing housework chores and getting places using transportation.

In-depth interviews conducted with women with breast cancer for my thesis also show similar results. Most participants defined their physical complications as a result of treatment procedures. Results of my field study shows that the most frequent side effects are lassitude and pain. The participants frequently noted that, due to severe fatigue they experienced, most women with breast cancer have difficulties in daily tasks. It is relatively easier to overcome lassitude when there is a willing caregiver to provide the patient basic tangible needs. However, when patients try to overcome this process on their own, fatigue decreases their quality of lives. For instance, Thistle (46, single, no child, informal sector) tried to overcome all treatment process alone. She explained the huge impact of fatigue on her daily life as follows:

> I remember in a July day, I couldn’t get up from the bed to drink a glass of water. Think about it. All day in a hot weather, you cannot drink a glass of water. I cried. It was an awful situation. You don’t want to be dependent on somebody else but you cannot drink even a glass of water.

Similarly, most of the cancer patients under consideration suffer rigorous and lasting pain. It reaches its peak point after the surgery. Treatment-induced pain continues during chemotherapy and radiotherapy. Most of the patients have difficulties in their daily tasks because of this pain. Lymph edema is another important physical impact of cancer treatment. Indeed, some participants declared that they have serious troubles in arm movement due to surgery. During and after chemotherapy, persistent side effects including pain and lymph edema decrease their physical function. This is well expressed by Black (60, married with 6 children, housewife) as follows: “My arm really hurts. They (doctors) took all of my lymph and it is really a huge pain. You cannot move your arm.”

Not only surgery and chemotherapy, but also radiotherapy has its own side effects on women with breast cancer. Radiation therapy is a local practice, so its main impact is seen on the region of the body where the tumor is found. Actually, interviews indicated that main side effects of radiotherapy are dryness, itching, blistering, and skin changes. According to the participants, this treatment procedure is extremely painful and can create permanent skin changes. The location where radiotherapy is applied may get darker or varied coloration as a long term side effect. Although radiation therapy is generally defined as an easier procedure than chemotherapy, its side effects, especially skin changes last for years. Therefore, some patients might have second-thought about treatment due to its severe side effects. Indeed, Orchid (45, married with two children, formal sector) said that

> If I didn’t have a husband and children, I would have refused the treatment. It is really hard. Radiotherapy burns your body. Your skin becomes fully black. It is like a hell. Every day they burn the same place again and again. Think about it; you have a scar and they put something into it. Sometimes I see other people who have the same scar on their body and I know they had radiotherapy.

In some cases, this treatment can cause permanent health damages. For instance, Thistle (46, single, no child, informal sector) uttered that “my radiotherapy affected my thyroid gland and now I have hypothyroid. But I have nothing to do. In order to save a part of your body, you harm another part.” Therefore, patients can face other illnesses due to cancer treatment process.

All these physical side effects have enormous influences on daily lives of women. As discussed in a previous study, the highest ranked home care needs are housework, cooking and cleaning (Ertem, Kalkım, Bulut & Sevil, 2009). Actually, most patients under consideration reaffirms the results of this study by stating that they experience austere complications in housework. Most participants remarked that they cannot handle even the simple cleaning tasks. Standing on their feet for long time can be devastating, thus in some cases washing dishes can induce suffer and distress. Indeed, a group of interviewees, who had a surgery for the removal of lymph, defined themselves as disabled. However, it is possible to state that most participants were ready for these side effects before they were actually occurred. Actually, they take them granted, similar to the results of a previous study. In this study, women with breast cancer described their problems in daily activities as ‘taken for granted’ (Macdonald, Bruce, Scott, Smith & Chambers, 2005). The other side effects of cancer treatment process are taste and smell changes. During treatment procedures most patients undergo smell changes, oral problems, nausea, and appetite loss (Bernhardson, Tishelman & Rutqvist, 2008). Due to these reactions, almost all of the patients participated in my field study also reported that they cannot cook or eat as they could before the diagnosis. Thus, patients predominantly try to overcome these difficulties in cooking with the help of female family members or relatives. If they cannot find any support in cooking, some of them cover their mouth and nose with a mask and struggle to cook.

Although these factors are undoubtedly significant, issues associated with body image of women with breast cancer can also emerge in this process. Appearance changes, weight gain or loss, and chemotherapy-induced alopecia are one of the most distressing side-effects of cancer treatment procedures (Helms, O’Hea & Corso, 2008). It would not be an exaggeration to state that considerations about body image play a major role in their decisions for surgical operation. Indeed, their decisions are also affected by various variables such as age, socio-economic and marital status and existence of child as well as cultural factors. For instance, my interviews demonstrate that while elderly married women with children can be more prepared for breast surgery, younger women are more afraid about changes in their body. Especially younger women with higher socio-economic situation are more concerned about body image related with mastectomy and potential reconstruction, hair loss and weight gain or loss. These are also parallel with the results of previous studies. For instance, a self-report questionnaire, aiming to understand changes in body image during cancer treatment process, provides important insights on this issue. The results of this study show that body image and feelings of attractiveness are among the primary impacts of treatment process (Rowland, Desmond, Meyerowitz, Belin, Wyatt & Ganz, 2000).

The other distressing physical side effect of cancer treatment process associated with body image is alopecia. Although surviving and healing become more important during this period, the literature is replete with studies in which hair loss is ranked as the most challenging side effect (Lemieux, Maunsell & Provencher, 2008). However, some health services like good preparation for hair loss, individual attention, and continuity of care reduce distressing impact of alopecia (Wagner & Bye, 1979). Women with breast cancer experience severe social and psychological difficulties due to appearance changes. Indeed, my interviews showed that stressing symptoms of hair loss starts even before it actually emerge. Most participants knew that their hair would be lost at the time of diagnosis and it was a traumatic event:

> Hair loss was awful. I couldn't take a bath for long time fearing that I will become bald. At the end, I went into the bathroom and locked the door, started washing my hair while my eyes were closed. When I opened my eyes, I saw that the bathroom floor was full of my hair. That was terrible. I cried in the bathroom. (Pink, 34, married with 1 child, informal sector)

To cope with negative effects of hair loss, cancer patients try to develop several coping strategies. The most common strategy is camouflaging and hiding. Most of them wear wigs. This coping strategy aims to decrease social and psychological difficulties which they are experiencing.

5. 1. 2. Caregivers' Experiences with Physical Impacts of Breast Cancer

As revealed by the interviews conducted for this thesis, family caregivers are one of the most important factors in optimal treatment, social support and physical care. The cancer diagnosis generates a chief crisis not only for patient but also for patient's family members. Family members assume this role suddenly without prior preparation and support from the healthcare system. Caring for a family member with cancer presents noteworthy challenges, with extensive psychological, economic and physical consequences for the caregiver. In order to meet all needs of cancer patient, lives of family members can also undergo radical changes. Cancer can lead to changes in their daily routines, professional lives and even personalities.

One form of care, tangible support, refers to providing support in a physical way, for example, helping someone with tasks such as cooking and cleaning (Hirschman & Bourjolly, 2005). Physical (tangible) care is the most time consuming part of needs of cancer patients. House cleaning, cooking, transportation and personal care require a huge effort and time. In most instances, family members revolutionize their life styles in compliance with patients' needs and side effects of treatment process. For instance, daughter of a cancer patient suspended her education for a year and stayed with her family to meet the tangible care needs of her mother. This case also proves that female family members or relatives are more likely to undertake tangible responsibilities. As expressed by her mother:

> My daughter managed all cleaning. She suspended her education for a year and stayed with me. She changed my sheets in every three days. Because during the chemotherapy, you get disturbed even by your own smell because you don't smell like yourself, you smell drugs. (Purple, 45, married with 2 children, housewife)

In some cases, hiring a full or part-time helper in house would decrease the burden family members feel. Some tangible needs are provided by a helper such as cleaning and cooking, and thus family members undertake less responsibility. However, only economically advantaged families could afford a professional helper at home. In a lack of economic power to hire a helper, all tangible needs are handled by a family member. This is also verified by daughter-caregiver of Purple, breast cancer patient mentioned above:

> I always changed her bed sheets and ventilated her room. Now I look back and say that if we had a helper in our home back then, our responsibilities would decrease and it would be easier for us. (Orange, Woman, 23, Daughter, Caregiver).

Needs, expectations and problems of women with breast cancer vary along the illness path. This is also applicable for caregivers. As suggested by the findings of a study, the quality of life of caregivers of cancer patients fluctuates throughout the illness trajectory (Kim & Given, 2008). Similarly, most of the participants interviewed for this thesis also noted this fluctuation during treatment process. For instance, within the four or five days after chemotherapy, tangible needs of patients reach a peak due to severe side effects of treatment. Correspondingly, as a result of the fact that cancer treatment is a long process which can last more than a year, care-giving can create a huge burden on family members after a while. This can increase psychological troubles of patients. For instance, Green, who is under treatment of her second cancer, explained her husband's attitudes toward her as her primary caregiver:

> During my first cancer treatment my husband cooked and cleaned the house. To be honest, he took care of me very well. But after a while, I started to bore him. In my second cancer treatment, we found a helper. If we didn't have economic power, I don't know what we could have done. (Green, 51, married with 2 children, retired)

Thus, tangible needs of cancer patients can create huge burden on family members. It necessitates their continuous efforts. Families try to be more flexible in modifying daily tasks. With this aim, they try to hire a professional helper, when economically affordable. Yet, in other cases, most family members try to make huge sacrifices to compensate these needs.

5. 2. Living with Psychological Impacts of Breast Cancer

In this part, the focus will be on the psychological impact of breast cancer on patients and caregivers and the impact of treatment process on the emotional adjustment and coping strategies of patients and caregivers to the disease. Based on result of in-depth interviews, reactions of the patients and caregivers to cancer diagnosis and treatment process will be explored. Most psychological and social care needs are still not included in organized social services provided by governments (Hoch & Hemmens, 1987). It is possible to claim that this is also case in Turkey. Therefore, almost all women with breast cancer try to handle psychological challenges with the help of informal aid channels provided by family members, relatives, friends, neighbors and social support groups. Only a limited number of women with breast cancer could afford a professional psychological support, for the reason that health system in Turkey does not consider psychological needs of cancer patients and caregivers. The way in which patients and caregivers cope with breast cancer throughout the treatment process shows differences. Side effects, resources and personal needs determine the coping strategy as well as subjective determinants such as personality, age and socioeconomic status of the individual. Accordingly, different challenges and expectations may arise.

In order to understand the psychological challenges of cancer and its treatments, psycho-oncology has been started as a field (Greer, 1994). The psychological oncology literature produces normative and statistical data on the problems, needs and expectations of cancer patients and their family members. According to a psycho-oncologist who was interviewed for this thesis, it covers different types, stages, and treatment specific concerns of patients as well as role of social support and family adaptation. In other words, it analyzes the impact of diagnosis and treatment process on cancer patients. Yet, psychological oncology adapts medical model in which it classifies patients according to their psychological reactions to cancer instead of socioeconomic and cultural factors (Mathieson & Stam, 1995). Similarly, as noted by the professional psycho-oncologist interviewed, this field is not well-developed professional and theoretical area in Turkey. The main reason of this is that psycho-oncologists who can consult cancer patients should take an oncology education in order to support cancer patients in coping with impact and treatment-induced side effects of different cancers.

Not only in the field of psycho-oncology, cancer is generally thought as a personal problem to be solved in many fields, mainly through the adoption of appropriate coping strategies. Yet, psychological problems, which women with breast cancer face during and after treatment, should not be treated as only individualistic stance, but rather should be analyzed in a holistic approach (Wyatt, Kurtz & Liken, 1993). In a holistic approach, cultural factors, socioeconomic status, felt emotional support and coping resources play important roles. Thus, in this part, psychological impact of breast cancer on patients and caregivers based on semi-structured in-depth interviews will be analyzed, by trying to use holistic approach.

5. 2. 1. Patients' Experiences with Psychological Impacts of Breast Cancer

Imagine that you are a woman in late forties. One day you learn that you have a breast cancer. What would be your feelings? Fear of death, loss of a breast, corruption in life routines, your children, your husband, your job or future plans? Or, all of these and other feelings at the same time? Yellow (53, married with 2 children, housewife) explained her feelings as follows:

> Doctor looked at my test results and said I have cancer. No matter how you prepare yourself, you feel awful. When I heard that name, my whole world collapsed on me. I felt like everybody is happy except me. I am sick and I am going to die.

There is a variety of common experiences creating psychological problems on women with breast cancer. One of the most frequent experiences throughout this process is the lack of personal control over the cancer treatment process and uncertainty about outcomes. The psychological responses to cancer diagnosis change in a continuum between sadness, hopelessness, anxiety, anger and denial. Psychosocial factors play important role in modifying these responses, such as age, specific type of cancer and treatment, culture.

In-depth interviews conducted with women with breast cancer for my thesis indicates common patterns. The diagnosis and treatment process of cancer have huge psychological impacts on patients. After the diagnoses of cancer, women under consideration stated that their first reaction was shock and fear. After the first shock, they habitually experience extreme sensitivity, vulnerability, desperation, anxiety and fear of death. The most referred reason of these psychological troubles was that the clinical treatment procedures and outcomes are vague and unclear. And also, the partial or imprecise information about the cancer treatment process also create nervousness and resentment on women with breast cancer. Most patients have some doubts about the treatment process and possible side effects, as well as their treatment outcomes. This is mainly because recovery and positive treatment outcome cannot be guaranteed. Even after the treatment process, most of them fear that the cancer will return. It is possible to state that the fear of the cancer is spreading or returning back is the most common source of psychological stress among women with breast cancer. Actually, my field study reaffirm the results of a previous study on this issue. A systematic review on quantitative studies shows that the fear of cancer recurrence is among the most commonly reported problems by cancer patients (Simard, et al., 2013). Indeed, the transition from cancer patient to survivor is a process of progression with unmet needs (Burris, Armeson & Sterba, 2015).

Each woman tries to overcome the psychological troubles led by this process by using different coping strategies. Moreover, age, socio-economic status and life change also play an important role in the adjustment levels of patients. Symptoms and side effects caused by cancer treatment process are other factors that influence coping strategy and quality of life of patients. Based on the findings of this study, it was not possible to identify coping strategy patterns of the participants in accordance with their specific features. Yet, I can still define the different coping strategies of women with breast cancer. There are mainly four coping strategies namely disclosure, professional support, social groups and spiritual meaning-attribution. For instance, according to Bloom (1982), social support that women experience affects the adjustment process by improving their coping ability.

Disclosure of an illness, psychological reactions and experience may enhance the access to social support. Pistrang and Barker (1992) described telling others about breast cancer as one of the most effective coping strategies. Another cross-sectional study also indicated that less talking about cancer causes greater levels of depression and less well-being (Cordova, Cunningham, Carlson & Andrykowski, 2001). Actually this was also the case in my field study. Indeed, in my interviews, it was seen that a proportion of women chose not to tell other people about their diagnosis. However, women with breast cancer also use nondisclosure of their illness as a coping strategy. The field study conducted for this thesis showed different patterns in their disclosure patterns. While some of them share all their emotions with their families and friends, others hide their illness and keep it as a secret. In fact, social support plays an important role in the adaptation of breast cancer patients and in the reduction of psychological suffering. Non-disclosure in these women was found to be associated with afraid of getting disappointment. Women with breast cancer who can explicitly talk about their fears and concerns mostly complain about being misunderstood and slurred over. On the other hand, some participants stated that they do not want to converse about cancer and their emotions. The main reason of hiding their illness is the fear of getting disappointed. As noted by a participant, in some cases they act reluctantly when sharing their illness with their family members. They do not want to expect something from others because if they do not meet their expectations they would have feel worse. In other words, they are afraid to have expectations which will never be satisfied by their families and friends. This point is well expressed by Lavender (55, divorced with 2 children, teacher):

> I didn't want any psychological support from my environment because I didn't want to feel like a potential deadly patient. I did not even share my illness with others. I did not want to expect care or support from others. I was afraid to be disappointment.

Nevertheless, it is still possible to state that social support plays a crucial role in overcoming challenges of cancer lightly. The importance of social support has also been discussed in other studies. For instance, if a patient considers her coping resources adequate, the degree of threat that she feels decreases (Yola, 2011). Another study also indicates that most vulnerable breast cancer patients are those who had minimal social support (Kornblith, et al., 2001). Thus, interpersonal relationships play an important role in the adaptation to serious illnesses (Simard, et al., 2013). Regardless of coping strategy in terms of closure and disclosure habits, most women with breast cancer can still experience depression or anxiety after the diagnosis and throughout the treatment process.

Most of the psychological responses associated with diagnosis and treatment are often tried to be solved by a patient's own psychological resources like family, friends and neighbors. Only a few participants confirmed that they regularly consult a psychologist to lessen their cancer-related stress and anxiety. It is possible to state that consultation enable them to cope with the psychological and behavioral aspects of the illness. According to these participants, professional psychological support increases the coping ability of women with breast cancer and also endorses their emotional well-being. Regular and well-structured consultations which are organized according to needs and expectations of cancer patients would help to improve their adjustment to cancer treatment and increase the effectiveness of treatment process. An interviewee who could afford regular consultations, Violet (43, married with 2 children, retired) expressed this point as follows:

> I controlled all my emotions. If I started to think about my illness I would have sink like a stone. I have no one to support my back. To find this power, I regularly see a psychologist. It was really helpful for me. But it is really expensive. I could afford it but most people cannot.

Therefore, it is a huge lack that oncology centers and hospitals do not employ a psycho-oncologist.

The third coping strategy is consulting to social support groups. Some women with breast cancer participate in social support groups to expedite their adaptation to cancer. Indeed, some participants of this study were members of the social support group namely *Bir Yaşayan Bir Bilen*. This association is founded to support and enhance the quality of social lives of women with breast cancer. This social support group organizes trainings and social activities which are appropriate to their physical conditions, such as painting, singing or drama courses. Almost all participants who were members of this association mentioned this group as the biggest opportunity for them to adjust the treatment process and idea of being cancer. Moreover, this group provides a feeling of not being alone because in this group, women with breast cancer can share their feelings, fears and questions with them. Therefore, these kinds of groups can play an important role in coping procedures of women to this process.

And the last coping strategy is to attribute supreme and august meanings to cancer. Some participants mentioned their illness as luck or a spiritual sign. Most of them described cancer as a life-changing event because they said that now they are totally different from the person who they were before the illness. They believe that cancer is a kind of sign or test sent by God or life to them. Now, to be grateful and happy for little things become important parts of their lives. Almost all women under consideration try to incorporate spirituality and religion into their treatment experience. They noted that the various aspects of religion and spirituality played a great role in their coping with breast cancer. Even some participants found strength and tolerance, which are necessary to cope with fear and anxieties during this process, in faith and trust in God. This coping strategy plays an essential role by giving encouragement that God will take care of them through their illness. My results also reaffirm the result of a previous study. As can be seen from the results of the qualitative study conducted by Holt and McClure (2006), spirituality and religion are among the most repetitive concepts when it comes to coping with cancer. This point is also put by a participant, who attributed a “holly meaning” to their illness, as can be seen from the following case:

> I personally believe in that everybody has a challenge in this world. So I am tested by life via cancer. Maybe I had some steepness. Cancer is given to me to face these lacks of mine. Thanks God, he gave me this. Now I am thankful for everything I have. This is a wonderful feeling. (Magenta, 43, married, no child, housewife)

Another major psychological impact of the cancer treatment process on women with breast cancer occurs in their social life. Cancer treatment can affect the types, frequency, place and time of social activities they attend. As discussed earlier, cancer treatment is a long process with severe side effects. For these reasons, social lives of patients are exposed to major changes. The results of my field study show that there are at least three main reasons underlying these fundamental changes seen in their social lives. First, physical and psychological side effects of the diagnoses and treatment process result in unwillingness in social life. Two main difficulties for patients in socializing are defatigation and pain. Moreover, women with breast cancer usually concentrate on their own lives and the treatment process, thus they hesitate disturbing their environments with their personal problems. In other words, they stated that if they go out to meet their friends, cancer and side effects will be the only thing they will talk about.

The second reason underlying the problems in their social lives is the fear that they might be adversely affected by the exposure to environmental microorganisms and germs. Most of the participants noted that they are afraid to leave their home to go public places such as shopping malls and restaurants. At public places, there are germs and pollution which might create health problems due to weaknesses in their immune system. For instance, Purple (45, married with 2 children, housewife) expressed her fears regarding public places with the following words: “I cannot go to shopping malls, because they are full of microorganisms. I got infected in these places. All of my body hurts. I know it, I feel it. I got infected.”

And the last reason of social problems is the feeling of discomfort in public places due to glances and behaviors of people. Some participants stated that in public places they are exposed to disturbing glances. The main reason of this is the changes in their appearances due to treatment process. For instance, baldness caused by chemotherapy make them disturbed. This is uttered by Orchid (45, married with two children, formal sector) as follows:

> In Turkey, people are really bad. Once we went to a restaurant for a dinner, a family got disturbed by me and changed their table to not seeing me. They changed their table while showing me to the waitress. Maybe they thought that my illness was infectious. Maybe they got sad for me and couldn’t continue their dinner due to this sadness. I don’t know. But it was really bad for me.

To overcome these difficulties faced in social lives during treatment process, family members, close friends and relatives can be considered as the main social support providers. Social support functions as a protection of the relationship between the women with breast cancer diagnosis and their illness experience. But there is a huge doubt whether these groups can be sufficient to solve these social problems. In other words, real social support and perceived social support might be different. My findings show similarity with previous studies conducted on this issue. As can be seen in a qualitative study conducted to understand unmet needs of women with breast cancer, lack of emotional support is one of the most important unmet needs during cancer treatment process (Pedersen, Hack, McClement & Taylor-Brown, 2014). To summarize, as discussed by Tuncay (2010), only medical treatment including chemotherapy, radiotherapy and surgery cannot be enough for healing. A well-developed and well-structured health system should include psychosocial support during and after the treatment. This is vital in enhancing adjustment process of patients. Also, regular psychological consultations might improve the treatment outcomes.

5. 2. 2. Caregivers' Experiences with Psychological Impacts of Breast Cancer

Each year, a number of women is diagnosed and must cope with the disease and treatment of cancer. They do so with the aid of their families, friends, and the health care system. Unfortunately, psychological interventions are not sufficient in Turkish health and social policies. This absence raises the importance of the role of caregiver. Actually, increased burden on caregivers leads to reduced psychological and physical well-being (Morimoto, Schreiner & Asono, 2003). A study analyzing anxiety and depression symptoms of family members of adult cancer patients showed that caregivers also experiences psychological challenges during treatment (Compas et al., 1994). The interviews conducted with caregivers for this thesis also showed that treatment process create huge psychological impacts on caregivers. Cancer of a family member changes lives of other members and they place themselves in a new role as caregiver. Lives of caregivers undergo a drastic change, because after the diagnosis, life routines of caregivers are reorganized according to the needs of women with breast cancer. They become responsible for maintenance of basic care needs and support. Caregivers also have worries and fears related with possible side effects of treatment process and treatment outcomes. For these reasons most of them are affected psychologically.

Partners and other family members are fundamental support resources for cancer patients. Some can cope without facing any strains with the care-giving role but a substantial part become extremely anxious. Indeed, a study conducted with caregivers draw a picture about general tendencies of them. Female caregivers and those with a history of psychiatric disorder are more exposed to stress and depressing impact on their lives (Pitceathly & Maguire, 2003). Due to the few number of caregiver participants, it was not possible to deduce general characteristics of caregivers from my field study. However, it is still obvious that they experience difficulties while trying to handle the responsibilities. To meet these responsibilities, demands and needs of the treatment process, caregivers might have psychological challenges, such as fear, depression and anxiety and this process can make them feel lonely and fragile. It is a well-known fact that care-giving is perceived as a moral obligation for family members in Turkey. Therefore, psychological difficulties are often not easy to talk about. But most of the caregiver participants admit that it is not always easy to accept and adapt to the transformation in routines of life.

This transformation can be occurred in different parts of their lives. As mentioned above, care-giving is a multidimensional phenomenon. Some caregivers are responsible for providing transportation to women with breast cancer. Several others supply care at home and meet physical needs. And some caregivers try to meet the emotional needs of patients. My participants also showed the similar patterns. While some were responsible only for transportation, some other are providing emotional support. Actually, there is a gendered division of caregiving. This issue has been also discussed in literature. A study investigating the influence of gender on the division of responsibility among adult children who are providing care also shows (re)negotiation of gender (Hequembourg & Brallier, 2005). It presents the impact of gendered division of care on the familial relations. Indeed, as presented by Daly (2002), women are seen as the main caregivers because of culture of social obligation. Social obligation firstly defines women’s role as mothers, yet it can also be seen in cancer care. In fact, a close analysis of interviews shows that in cancer care, women are seen as the main provider of care except the dimensions of transportation and economic support. On the other hand, male caregivers, like sons and husbands, are mainly responsible for transportation and economic issues. This can also be defined as culture of social obligation of women to provide emotional and physical support. Indeed, “protective guardian” term helps us to understand the adaptation of spouses in their new care-giving role during their wives’ hospitalization, which is linked to male gender roles (Sabo, Brown & Smith, 1986). No matter what is their responsibly, caregivers are influenced by their new roles. Most of my participants mentioned the huge negative impact of this process on their lives. According to a study conducted with close relatives of women under treatment for breast cancer indicates that highest rated unmet needs regarding emotion and support network is to have less time for themselves (Schmid-Büchi, Borne, Dassen & Halfens, 2011). This study also shows similarity with the results of my interviews. Most of the participants mentioned the negative impact of their caregiver role on their personal lives in terms of having less time for their own lives. In other words, most of them felt highly psychologically distressed due to lack of personal time.

On the other hand, the psychological troubles of cancer patients might create sorrow on caregivers. According to my participants, they feel desperate when caregivers cannot help to reduce the stress and anxiety levels of women with breast cancer. In other words, when patients try to keep their emotions as a secret and do not share their feelings and fears, caregivers feel worse. Exclusion of emotional dimension from the care fields provided by caregiver also devalues the role of a family member. The case of Brown (Man, 55, Husband, Caregiver) shows the impact of the personality of a woman with breast cancer on her caregiver:

> My wife never talked about it. This is her characteristic. But her silence devalued my role in care. I would prefer to share her feelings instead of providing her only transportation. All of them were the common feelings. We had common fear, common joy, and common pain.

Therefore, it is possible to question this gendered division of care. In some cases, male caregivers also want to touch upon emotional care needs of patients. No matter how this process influences them, caregivers do not question their role. The illness is taken for granted and many caregivers undertake major responsibilities with a less negotiation. My field study showed that generally an emotionally powerful individual undertakes main responsibilities. Anxiety, sadness or fear of caregiver does not change their point of view about their role. To have a family member suffering from cancer legitimates the care-giving position. And in some cases, participants may legitimate their roles as a result of loyalty to past endeavors of the patients as a mother or wife. The following case illustrates what I am arguing:

> While I was working, my wife used to take care of me very well. Every morning she used to prepare my outfit including my socks. This is so important for me. Not even for a day she complained or made a face. She supported me in my economic and emotional problems. Of course I will take care of here, in such a time. (Ivory, Man, 49, Husband, Caregiver)

Although caregivers experience huge psychological troubles in their lives, they take these troubles as granted. Therefore, they do not habitually generate a coping strategy. Still, a few caregivers said that they take professional psychological support to overcome difficulties during this process. However, only economically advantaged caregivers can receive professional consulting because in Turkey there is no regulation concerning psychological conditions of caregivers. Hence, a well-developed and well-established psychological support should include a range of supportive services enhancing social environment in which women with breast cancer live. The professional psychological support ensures to overcome the difficulties in the process more easily. Some participants said that they are using antidepressants in order to control their emotions during this period. In some cases, troubles and difficulties of providing care to patients with cancer can create stress-induced diseases in caregivers. Indeed, unexpressed feelings can adversely influence health of caregiver. This is well expressed by Brown (Man, 55, Husband, Caregiver) as follows:

> I am not complaining, but it was hard for me. I got herpes zoster and this illness is rooted in stress caused by my wife's cancer. To be honest, we had really bad days but if I tell you about it I will feel worse. We should accept it and try to overcome all difficulties.

To sum up, like previous studies on this issue, my field study also shows that there should be interventions and supports to decrease burden, depression and stress of caregivers. This can increase their quality of life and equip them with necessary knowledge and coping strategies which would also enhance the quality of care they provide.

5. 3. Living with Economic Impacts of Breast Cancer

After the shock and anxiety, which are the first reactions to cancer diagnosis, patients and families start to wonder about high prices of cancer care. As discussed in the previous chapter, health system in Turkey provides the basic treatment options and drugs free of charge. Health insurance covers medical expenses including doctor appointments, imaging tests, radiation treatments, hospital stays, surgery costs and chemotherapy. Yet, there still remains an enormous lack in direct and indirect expenses regarding cancer treatment. Many people have no idea what to expect financially when a family member is diagnosed with cancer. This is mainly because while some expenses are clearer than others, the hidden costs of cancer also create huge troubles on families with cancer patient member.

One can safely argue that cancer influences people financially more than they expected. Taken for granted expenses often include costs like particular drugs, supplements, transportation, new equipment necessary during this process and in some cases loss of income of patients and caregivers. However, in most cases some expenses create a great shock and burden on household budget. For instance, as it will be discussed below, in some cases patients and families need to travel to different cities for treatment, because human resources and treatment equipment are not equally distributed among different regions. Additionally, some families might need child or elderly care to regularly attend their treatments. Due to the severe side effects of the treatment schedule, some patients, and also caregivers, may need to work less. This condition yields to loss of income in families when the need arise. For these reasons, cancer is an expensive disease, which gives consummate encumbrances on families with a cancer patient member. Thus, one can argue that the current health system in Turkey, which only provides the basic medical expenses, is not sufficient to protect the quality of life of patients and caregivers and escalates their financial suffering.

5. 3. 1. Patients' Experiences with Economic Impacts of Breast Cancer

The economic impact of cancer is huge and women with breast cancer are likely to experience pecuniary distress. In this part, I will try to understand cancer-related out-of-pocket expenses and their impact on quality of life of patients. A close analysis of the in-depth interviews shows that economic burden, rooted in cancer, is more felt in single women with breast cancer. They try to defeat economic troubles by themselves alone. On the other hand, married women are more likely to leave monetary issues to their husbands to handle. This quasi division of responsibilities decreases the stress and anxiety of women with breast cancer entrenched in economic issues. Yet, there remains a huge gap in direct and indirect out-of-pocket expenses needed to be covered.

As revealed by my field study, the majority of out-of-pocket costs were for co-payments in private hospitals, transportation, professional help for housework and cooking, supplementations and special arrangements necessary during this period, such as special waters, cleaning materials and so on. Even among women who used only transcript treatments, the economic burden of breast cancer can be substantial. These results are parallel with the results of previous study about insured women. In this study, the most commonly reported out-of-pocket expenditures were medications, transportation, physician visits, and restaurant meals (Arozullah et al., 2004). In a similar vein, I will group out of pocket expenditures which were seen in my field study under four subheadings, namely medical expenses, transportation, professional support in home and loss of income.

One of the most common out-of-pocket costs is medical expenses. According to the interview which I have conducted with the oncologist, in the treatment of breast cancer there are mainly three levels. Firstly, surgery is regularly used in order to physically remove a tumor. Second is chemotherapy that kills fast-growing cells through chemicals. Radiation therapy is another form of expensive cancer treatment. It necessitates a frequent treatment schedule. Cancer drugs and treatments are really expensive and health system in Turkey supplies only the basic treatment opportunities. However, there are disparities in health care due to different drug reimbursement decisions taken by each health care system. Countries make different decisions regarding which cancer treatments would be routinely provided (Pujolras & Cairns, 2015). In Turkey, doses, process and type of treatments are all predetermined by the health regulation. All patients are subjected to the similar treatments without regarding their differences. As mentioned during the interview I conducted with the oncologist, personalization of treatment is an important component of high quality cancer care, thus most women with breast cancer try to personalize their treatment by themselves which cost extra expenses.

Not only the special treatment arrangements but also the basic treatment procedures supplied by the government are problematic. Almost all participants said that they have got their chemo and radio-therapies in public hospitals, but for surgery they mostly choose private hospitals, although it necessitates a considerable amount of payment. The costs per surgery vary greatly, depending on the hospital, doctor and type of the procedure. However, families and patients are ready to sacrifice required payment for surgery in private hospital. What is more, in some cases basic drugs and procedures which were supplied by social security institution are not sufficient to ensure recovery. Especially for higher staged patients, more effective and powerful drugs and procedures are necessary and they are generally much more expensive than the regular ones. Thus, access to the necessary treatment which can successfully treat cancer often requires high amounts of money. People who cannot afford them usually do not receive the best care available. The following case would be seen as a proof of this point:

> Government does not provide anything. It applies the same method of treatment to everyone without regarding the differences in illness. Even some drugs necessary for this treatment are not supplied by our insurance. The government finds cheapest and newest drug and only provides it. But some other drugs are also necessary for healing. Government's responsibility does not finish by giving radiotherapy. (Crimson, Woman, 51, Upper sister, Caregiver)

It is possible to state that best care for each person show differences according to tumor type, cancer stage, age, and other personal characteristics. But, this also creates extra economic burden on cancer patients and their families. For instance, Orchid (45, married with two children, formal sector) expressed economic burden generated by additional medical needs as follows: "I sold a house to compensate my expenses during my treatment. We have insurance but my special drugs are really expensive. My cancer is in the latest stage so I have to use some special medications. I hired a specialist so I have to pay the difference”. Personalized medicine is the most effective strategy to treat a cancer patient according to her inherited composition and her tumor type. Personalized medicine also diminishes potential side effects of standard treatments because it customizes treatment to each patient’s own needs. However, in Turkey, health insurance and public hospitals provide the same treatment to all patients without regarding differences in tumor’s type and stage. It became clear that some treatments worked better for some patients than for others. Therefore, as argued by Schilsky (2009), every health system should select the most effective, least poisonous, and most affordable treatment program for each patient.

Not only patients with specialized needs, but also women with earlier stages of breast cancer may pay co-payments for doctor appointments, tests or treatments. Actually, according to participants, in private hospitals, all procedures can be swiftly and easily completed. Also, staffs, including doctors and nurses are polite, caring and friendly in private hospitals. Withal, participants noted that private hospitals are much more hygienic and clean than public hospitals. However, tests and procedures often require patients to pay some money out of pocket, although the recent regulation strictly forbids additional payments to private hospitals. Indeed, almost all participants said that they got their chemo and radiotherapy in public hospitals due to subsidiary payments in private institutions. To be sure about their treatment, some women with breast cancer developed a coping strategy. They regularly visit doctors in private hospitals but undergo their treatments in public hospitals, where chemo and radiotherapy are free of charge. By using this strategy they feel their treatment is under control of a private doctor, yet they do not have to pay enormous amount of payment for tests and treatments in private hospitals.

Because of the need for repeated visits for cancer treatment, another financial concern that women with breast cancer must deal with is transportation. Some of the participants mentioned that they are regularly driven to hospital visits and appointments by their husbands or other family members. However, in the absence of transportation support from family members, patients must use the public transportation to the treatment site. There is an obvious difference in the quality of lives of these two groups of patients using different modes of transportation. For the former group of participants, long term side effects and fatigue due to treatment are felt in lower levels. However, they said that there were still some barriers such as availability of someone to drive them to the treatment centers and access to an automobile. Almost all of them need a transportation service which can reduce their feeling of indebtedness to others who drive them to hospitals. This feeling is understandable because most participants did not have any personal car.

On the other hand, patients who use public transportation to access the health center have a more negative perspective about the treatment process. Public transportation is associated with negative experiences during cancer treatment process. First, due to severe side effects of treatment, most of the patients feel themselves fatigue and weak. All paper works and the treatment procedures are long and troublesome processes. Especially after chemotherapy most of them feel themselves exhausted. Moreover, they generally have to wait for a long time at bus stops, to shift buses and other vehicles and they also walk to access the care facilities. All these might be tiresome for them. Another reason of their negative view about public transportation is their fear of getting sick due to their weakened immunity. Public places, like cafes, shopping malls, buses and metros are seen as dangerous spaces with dangerous microorganisms. Thus, it is possible to state that problems created by transportation play a significant role in their treatment decisions and schedules. Blue (54, widow with 3 children, housewife) describes her experience of transportation as follows:

> While my husband was alive, he used to bring me to the hospital. But now, I cannot come to hospital regularly. I miss some of the sessions. I cannot ask my sons every time. If I could call someone in charge to say “I have no one, help me on my transportation” we would have no problems. My home is really far away from the hospital. I know that dialysis patients are using special arrangements for their transportation. Why don’t we have that? Our illness is also a tough one.

What is worse, in the lack of efficient support systems in transportation, patients might waive from their treatment. Sometimes they are constraint to leave their treatment by difficulties in transportation, and sometimes they voluntarily waive their rights. This issue is also studied in literature for several times and generally gave similar results. Limited access to transportation significantly can cause to withdrawal from radiation therapy (Goodwin, Hunt & Samet, 1993; Guidry, Aday, Zhang & Winn, 1996). This is mainly because while chemotherapy is applied once in a three week, radiotherapy patients should get their treatments on a daily base for long time. While access to appropriate health service could be problematic in the same city, it would be to naïve to expect it to be easy to travel another city for treatment.

In some cases, patients had to change their cities to access the treatment opportunities. Although there are some local level regulations providing basic expenses of inter-city transportations partially, these arrangements are not sufficient and entail tremendous referral chains. In other words, decision about where to receive treatment is not up to the patients and families, but there are some rules determining the place where treatment will be taken. If a patient or family decides to get chemo or radiotherapy in another city, then they cannot obtain payment of a transportation expenses back from the Ministry. Thus to be eligible for payment of transportation, cancer patients should prove that there is no machine or equipment for treatment in their home city. In other words, if there is any equipment in their own city, a patient cannot apply for payment back. However, in many cases the treatment machine cannot be suitable for some patients' needs. Even in these cases, they still have to prove their eligibility for the payment.

Additionally, as discussed above, one should follow all the necessary steps of referral in order to take the payment partially. The case of Turquoise (52, married with 3 children, housewife) can be seen as a good indication of how these procedures can be discouraging for cancer patients to apply for the payment:

> We are coming from a different city. I heard that government gives half of your ticket money but it is a long process. They ask for referral and government doesn't give all of the money, they support partially. But it is really a hard and long process to apply and get this money back. So I did not try for it.

In addition to transportation, patients and caregivers should find place to stay in the city they went for the treatment. This also means additional expenses for accommodation, eating and other personal needs. The current regulations do not consider these kinds of expenses of patients and their caregivers. Although some municipalities have some local level services for accommodation and meals, they are not well-organized and well-structured. Indeed, most participants said that they did not even know these services. Furthermore, some mentioned how difficult it is to be eligible for these services. To sum up, these factors bring waive of patients from their rights for these services and yield extreme out-of-pocket expenses.

The other major issue that women with breast cancer must deal with is housework and cooking. As already discussed, due to severe side effects of the treatment process, most women with breast cancer recited their inability to handle housework and cooking. Thus, economically advantaged patients try to solve this problem by hiring a "helper". However, this also creates a burden on the budgets of families because hiring a "helper" for domestic work requires regular payment. To manage this payment, some woman with breast cancer should arrange all other spending. This also creates a huge emotional burden on women with breast cancer who see domestic works as their own responsibility, although they are common needs of all household members. Thus, women with breast cancer want to undertake all economic burdens led by the transfer of domestic jobs to a hired "helper". This can also be seen as an indication of the breast cancer patients' desire to protect their care-giving female role. But, for many hiring a "helper" for all domestic work can be economically impossible. However, living in a clean and hygienic environment is essential for cancer patients. As noted above, their immune systems are open to any kind of attack and they must be careful about this issue. Thus, one can argue that providing a clean and hygienic place to live for cancer patients cannot be seen as a luxury but as an extension of their treatment process.

Besides increased expenses, decrease in income also creates a huge economic burden on women with breast cancer and their families. In most cases, patients with cancer cannot continue working as they could before the diagnosis. Actually, according to a research analyzing the importance of treatment process on work lives of patients and caregivers provide important insights. Work ability during treatment process is associated with cancer type, type of treatment, health status, education and physical workload (Taskila & Lindbohm, 2007). Although the literature is replete with studies which prove the ability of cancer patients in continuing working, analysis of my in-depth interviews revealed a totally different picture, actually, most participants were already not employed before their illness. Only a small number of participants was working before the diagnosis. If they are eligible for retirement, some of them retired during their treatment as in the case of Cyan (46, married with 2 children, retired). She said that “I heard about my cancer and got retired. Because I didn’t know how much time I have got to live.” If not eligible for retirement, they gave a break to their careers. But, among them some participants, who were happy about working and their work environment are willing to return their work life after their treatment. This would also help them overcome the adverse effects of the treatment process. Indeed, a study conducted with cancer survivors showed that strong commitment to work organization and good social climate at work diminish reported impairment (Taskila, Martikainen, Hietanen & Lindbohm, 2007). This is also accurate for this study. Pink (34, married with 1 child, informal sector) who worked in an informal sector before diagnosis mentioned her decision as a break until her healing.

> Since my surgery, I have a health report so I do not work now. After my treatment, I will start working again. It is so hard to sit at home for someone who is used to work. So to speak, think about a free animal and you put her in a cage. The works you can carry on in home is very limited and I cannot do them. For example I cannot clean the windows.

Nonetheless, some women under consideration have to continue working due to financial deficiencies and lack of protective legislations in informal sector. Although working during breast cancer treatment and trying to balance all responsibilities along with recovery are really hard to handle, decision of continuing to work might be influenced by financial concerns and regaining normality (Kennedy, Haslam, Munir & Pryce, 2007). Women with breast cancer labor over to deal with all work responsibilities along with the effort of treatment. Lavender (55, divorced with 2 children, teacher) who continued working during her chemotherapy process is a salient example for this situation: “During my chemotherapy I continued working. My chemotherapies were on Mondays, I arranged them according to my day-offs. My boss didn’t know about my illness, so I had to hide all side effects”.

Due to lack of efficient and well-regulated cancer-induced work related policies in Turkey, women with breast cancer live difficulties in working life. Although formal sector has a protection and back up plans for cancer patients, in informal sector it depends on the attitude of employers whether cancer patients are protected or not.

5. 3. 2. Caregivers’ Experiences with Economic Impacts of Breast Cancer

Cancer treatment is a team battle and patients often rely on supports of their families throughout this challenging time. All of these supports and care cost families’ time and money. Illnesses, like cancer, necessitate long-term and multi-dimensional care which comprises the preparation and maintenance of healthy physical environment. This can include house work, preparing meals, and assistance in home health. To handle all these care needs, some families have to hire a helper to assist them with the challenges they face, including making meals and cleaning around the house. While economically advantaged families could hire a helper to reduce their burden in housework, others get help from female family members or relatives. Thus, it is noticeable that economic resources of families play a direct role in quality of lives of both patients and family members.

In addition to the expenses for the maintenance of physical environment, medical expenses can also create a huge burden on families. Indeed, some caregivers said that they had to borrow money from friends or relatives to handle these expensive supplements or private hospital expenses. Although these financial burdens force them, families try to reduce all other expenses to supply these needs of patients. In most cases, families try to overcome financial problems without patients' notice. When family members are analyzed according to their division of care, economic care, especially medical expenses, are undertaken by male family members. Indeed, housecleaning and foods are common needs of households. However, when it is economically possible, these needs are not treated as equally shared responsibilities, but more like a Temporary Threshold Shift (Melnick, 1991). This means a short-term change. Like the one in human's ears, human beings are remarkably tolerant of exploitation, and they apply several ways of protecting itself from damage when exposed to a crisis. Thus household members try to protect their inner dynamics of familial roles, mostly by using a temporary solution.

Transportation is another important spending item which creates extra economic burden for the cancer patients' families. Families without a car, try to deal with this need by asking favor from relatives and friends. This can also create an emotional burden on the family members. This is noted by White (Woman, 25, Daughter, Caregiver) as follows: "We don't have a car. We ask from a relative for transportation. Of course, we feel ashamed for asking, but we have no other choice." Families owning a car, on the other hand, try to drive patients to hospital visits regularly. In chemotherapy, caregivers drive patients for one time in every three weeks. Thus it is considerably easier to arrange time and money for this responsibility. However, radiotherapy is carried out every day for about three weeks. Thus, radiotherapy requires more physical and economic effort for families. Therefore, it is obvious that caregiving creates a financial burden on family members, both in total expenses such as hiring an assistant, medical expenses and transportation as well as in loss of income.

Many caregivers have paying jobs and at the same time try to handle their caregiver role which is another full-time job itself. As shown by a previous study, caregivers mostly experience challenges in their work life (Karabuğa-Yakar & Pınar, 2013). Care-giving can lead to work-related issues, such as missed days, decreased efficiency and work breaks due to medical appointments and other tasks. Even some participants have to take unpaid leave and/or decline their promotions. Thus, it might be difficult to balance work and caregiving responsibilities. Due to lack of effective and protective regulations about work lives of caregivers, family members attempt to take permissions from their superiors informally. When superiors are tolerant, caregivers can manage their roles much more easily. However, in other cases they face huge difficulties in balancing their caregiver roles. Beige (Man, 39, Son, Caregiver) stated that he had to spend all his permission days to keep company to his mother with cancer: "I have some difficulties in my work. It is a private sector, you know. My superior is a good one, so I can take permissions. But I have finished all my lieu days. I compensate my permissions by working overtime."

In order to diminish stress and problems rooted in conflict in work and caregiver responsibilities, family members try to pass duties to each other. Thus, when possible, division of caregiving is arranged according to the work life of a caregiver. For instance, if there is a retired family member, s/he takes the main responsibility, as remarked by Gray (Man, 50, Husband, Caregiver): "I could not have done all of these if I was working in private or formal sectors. I can handle all of these because I am retired. A boss who did not experience such an illness cannot understand a worker in this situation."

5. 4. Living with Familial Impacts of Breast Cancer

The high prevalence and huge burden of breast cancer forge considerable social costs. When breast cancer invades a woman, her family is affected by the treatment and care-giving experiences as a whole. This is mainly because each family member plays a specific role in caregiving chain and also in the family's everyday functioning. Also, patient, herself, experiences a formidable milestone in her life, because her priorities, psychological changes, social life, attributed roles and expectations (her and from her) undergo a radical change. Therefore, woman with breast cancer and her family members assume a new identity. These role changes also create a transformation in the dynamics and relationships within the family. Thus, cancer, as a life-changing event, forces all family members to modify their lifestyle and undertake new roles in care-giving chain. As already discussed above, breast cancer brings severe side effects, long-term care needs and economic burden to all family members. The main care and support are provided by family members including partners, children, parents and siblings. Thus, family members play an important role in cancer treatment process. It is possible to expect that as the incidence of breast cancer continues growing, role of family members as caregivers and these roles' impact on inner dynamics of family will gain more importance.

As need for familial care-giving rises, each family constructs its own understanding of care and care-giving style. This is mainly because each member and each family experience different kind and amount of burden due to these changes in familial relations. My field study indicates that these burdens can be related with symptoms of patients, behavior, socioeconomic characteristics, changes in household routine, familial or social relations, work and leisure time activities. To overcome these burdens and adapt familial dynamics to this new rhythm, family members generate different coping strategies. As discussed by Mormont (1992) these strategies show differences according to patient and caregivers' age, sex, role, cancer's site, stage, state, side effects, relationship of the caregiver with the patient (partner, parent, sibling, children), availability and accessibility of social services, health equipment and human resources.

Thus, it is not possible to generate a single and unique pattern of influence of cancer on every family and each family member. Another reason of diversity in familial outcomes is the discrepancy of familial resources. Families should utilize their financial, emotional and physical resources to handle cancer care, but they differ from each other in terms of their resources, motives and coping strategies. More importantly, in some instances, these differences among families and family members end up in cancer care disparities.

Additionally, differences among families have also repercussions on their decisions whether who would undertake cancer care and how division of care tasks would be shared among family members. All these kinds of decisions are made by family members and sometimes might result in disparities in terms of quality of care. Hence, it is very important to understand and analyze how families are affected by the cancer treatment process.

With the aim of understanding different impacts of breast cancer on familial relationships, this chapter will analyze the changes in the primary relationships within families from the perspectives of patients and caregivers. The main relationships which were stated by patients as the most damaged are child-mother, spouses, parents and siblings. For caregivers, parenthood, sibling and spousal relations are the most frequently specified links within familial dynamics.

5. 4. 1. Patients' Experiences with Familial Impacts of Breast Cancer

My field study revealed that breast cancer has a massive impact not only on the individual suffering from it, but also on the family members and relationships of a cancer patients. More specifically, when a member of a family suffers from a breast cancer, familial dynamics significantly change. Indeed, how a disease affects familial dynamics mainly depends on the role-changes of the patient. During cancer treatment process, there are several radical changes in familial dynamics as well as cancer patients' perception of family. For instance, in some cases, breast cancer can trigger new tensions within family and these tensions can fluctuate according to the needs and expectations of the patients. Furthermore, family members should arrange their time schedules, social activities and economic resources according to the needs and expectations of the patients. However, these can also be a source of distress and anxiety for the breast cancer patients.

Based on a close analysis of in-depth interviews, it is possible to identify at least three levels in terms of the breast cancer women's perceptions (and may be in some cases reactions) of familial changes triggered by their illness. More specifically, while some patients feel themselves guilty and mournful concerning these unavoidable changes, some others find familial changes necessary obligations. Furthermore, some see this transformation as a temporal period, while others assume them as permanent and steady changes. Still, some familial relationships may be weakened by these changes and negative experiences can accumulate, while other relationships get stronger and gain new precious meanings.

One of the most affected familial relationships of women with breast cancer is the relationship with their partners/husbands. Almost all participants were highly anxious about their spousal relationship. Indeed, they are afraid that their relationship or marriage will be damaged due to cancer treatment process or they will be separated as a result of increased emotional burden. Most of the participants gave examples about other women with breast cancer who divorced just because they as a couple fail to cope with this process. However, none of the participants has seen their relationships as a weakened one. Some patients noted that they made an explicit speech with their husbands when they first heard their illness. They knew that it would be a long and difficult process. For instance, husband of Pink (34, married with 1 child, informal sector) was really supportive and understanding during this process. She explained this as follows:

> I told everything to my husband from the beginning. I said that this will be a long and hard process and said that "You don't have to support me". I don't want to be indigent to someone because I have always been independent for all my life. He said that if I had the same illness, you would stay so I will take care of you. I am very thankful for him. My family's life has changed suddenly. I cried whenever I want but a man cannot do this.

One of the main reasons of this changes in partner relationship is the fact that patients cannot manage the things they could do before the diagnosis. For instance, women with breast cancer, who does most of the family's cooking, can't shop or prepare meals for several weeks during treatment. Thus, their husbands or other family members must take on this responsibility in addition to the tasks they already do. This role change might create a sense of dependability between spouses. This is primarily because in most cases, women make all housework and cooking activities as a result of internalized gender roles.

However, breast cancer creates a huge transformation in these functions. Due to cancer treatment's being a long process, patients feel in debt to their husbands, as expressed by Green (51, married with 2 children, retired): "Cancer makes you dependent on someone else. Think about a time process continues for a year. Who takes care of you for a year? It is so hard for a family."

While husbands try to undertake their wives' care needs and economic concerns, they also try to overcome fear of cancer and its spread, help patients deal with the emotional strains of the disease, and manage new time schedule caused by cancer treatment. Literature is replete with studies about sufferings from psychological impairment and mood disturbance as a result of the spouse's cancer (Blanchard, Albrecht & Ruckdeschel, 1997). To overcome these familial changes, family members develops new roles to help continue the main functions of their family.

Treatment process also creates deep impacts on sexual lives of spouses. Most participants said that due to relentless side effects and changed priorities, their sexual desire has seriously diminished. Their main disturbance about this deterioration is the fear about their partner's reaction. Some patients said that they would have understood if their husband would leave them due to lack of sexual life. Still, they noted that their husbands' approach was compassionate and tolerant towards them. Relationships after the cancer diagnosis are also reconstructed in the boundaries of gendered roles. This situation has also been discussed in literature. According to a study, husbands' care-giving experience and their new role in the women's eyes are shaped by these internalized gender roles (Ribeiro, Paul & Nogueira, 2007). Thus, it would be safe to argue that supporting a wife who is suffering from cancer attributes a new meaning to protective manhood role. This view is expressed by Orchid (45, married with two children, formal sector):

> We hired a foreign woman for cleaning from Ukraine. Think about it, there was a beautiful woman in home, who thinks you will die. "I can take her husband after she die." I felt them all. She was hitting on my husband. If my husband were tending to that kind of a relationship, I could have been homeless.

During this process, familial relationships gain new meanings. These meanings are mostly shaped by the belief systems and world views of families by rendering complexities and crises more bearable. As discussed above, religious traditions and belief systems generally enable patients and family members endure through the treatment process. For some patients, cancer represents a test applied by God to scrutinize familial links. This period is also seen as a kind of exam or test for their relationships and also for their husbands. While children, siblings and parents are accepted as morally obliged to care for family members with cancer, husbands' care are mostly appreciated and indebted as can be seen from the case of Cyan (46, married with 2 children, retired):

> This illness is a serious exam for a marriage because a woman with cancer thinks only about herself and doesn't give the priority to her marriage anymore. If my husband didn't support me, we couldn't have overcome it. He is a good person. I can see it now. Now I am sure we will take care of each other in our elderly. My cancer was his challenge: A challenge for his personality and his character. These are important exams for families.

Another changed relationship and identity during this process is motherhood. This changed relationship is also discussed in literature for several times. For instance, according to a study, the change is inevitable because cancer can threat the stability of a mother's parental role, undermining her ability to take care of her children and keep family together (Mazzotti, Serrano, Sebastian & Marchetti, 2012). Actually the perception of motherhood changes in terms of reactions to cancer treatment primarily in consonance with the age of the patient. To be more precise, for older women with breast cancer, both partners and adult children were important sources of support as revealed by a study conducted with older women with breast cancer (Maly, Umezawa, Leake & Silliman, 2005). This is also valid for this study. Older women with breast cancer expect more support from their children, while younger women feel more obliged to continue their motherhood roles in supporting their children. However, women with older children mostly feel less stress on them. Yet, it is still a challenging situation, because some participants believe that being a mother never ends, no matter how old their "child" is. Notwithstanding, older women with children still feel less stressed due to their changed parenthood roles. To illustrate, as already noted above, a patient’s daughter suspended her education for a year to care her mother. And in another example, Turquoise (52, married with 3 children, housewife) started to live with her married son, who is responsible her main care needs with her wife:

> My family is so helpful for me. If I had no one to take care of me, I couldn’t eat, go to the hospital. I can’t even think about it. If you don’t have any family, someone should be responsible for your food, cleaning and transport. Sometimes I feel bad about it because here I live with my son and his wife; I am kind of a burden to them.

Role of motherhood changes dramatically due to increased needs of women with breast cancer. A close analysis of in-depth interviews demonstrates that not only the age of the patient but also age of the children have a direct impact on the altered identity of motherhood. To be more specific, women with younger children feel more pressure and burden on them due to their changed functions. Studies analyzed younger women with breast cancer found some repeated patterns such as perception ‘out of sync’ and changed identity (Adams et al., 2011). Feeling out of sync and identity changes are also frequent patterns of my field study. Younger women with breast cancer are more concerned about their future because they have younger children who are dependent on them. During the treatment process, women with breast cancer cannot fulfill their internalized motherhood roles as they could before the diagnosis. Thus, they mostly mentioned their regrets and sadness due to this change.

On the other hand, learning the diagnosis of a mother creates a huge impact on children. Mother, the endless resource of care-giving, starts to a new period in which the relationship between mother and children will dramatically change. Older women with older children do not hide their illness from their children. On the other hand, younger women with breast cancer follow different disclosure paths to their children. A group of participants stated that they try to share their illness with their children. In these occasions, they have severe difficulties when they share this situation to their children, because they do not know how to say it without distressing them. Children who learned about their mother’s cancer can also give different reactions to this news. While some can receive this process positively and supportively, others might have troubles. They may experience social and psychological problems. In a case, son of Orchid (45, married with two children, formal sector) has abandoned the house during the treatment process:

> Cancer is a really challenging process. My son left the home abandoned us. (Starts crying.) But his leaving didn’t chance my role as a mother because I had to save him. I went his home in which he lived alone, cleaned the house, cooked for him. Just think! I have cancer and protected my son just to win him, not losing him. Maybe his behavior was a good thing for me because I didn’t get pacified.

On the other hand, in some families, women with breast cancer try to hide their illness from their children. Concealment has several reasons. Some does not know how to say, and how to behave. Some others are skeptical about the reaction of their children. And some women do not want to lose their caregiver role in the eyes of their children. In these cases, women with breast cancer try to hide treatment-induced hair loss by continuously wearing wig.

Closure and disclosure behaviors are rooted in the family communication patterns. As discussed by Rolland (1994), each family has its own way to experience the illness and handle risky topics. While some families employ open and direct communication, others adopt latent and constrained communication. No matter which way women choose, most of the participants of my field study have mentioned their increased expectations from their husbands as a father to their children. Side effects and treatment schedule bring a new form of division of child care between parents. Some responsibilities, formerly handled by mothers, are started to be carried by fathers. Coming together during difficult times also strengthens the bonds between family members. However, sharing child-caring responsibilities may also bring hidden tensions and antagonisms. For instance, Violet (43, married with 2 children, retired) said that:

> During my illness, my husband was abroad. Now he has a different kind of illness. He should not have any expectations from me because he was not there for me to support during my illness. Now he should handle all problems on his own." Think about it I had cancer, my daughter was ill; my father had a heart attack. I was alone and I handled these responsibilities on my own. We went to my surgery with my daughter and my father together because I couldn't leave them alone. If something happens the hospital would take care of them in my opinion. While I was on chemotherapy my daughter had a serious illness and we put her in hospital for a month and I got my chemotherapy in that hospital and spent a month for month. I didn't think about my cancer and myself for a minute, because my daughter was ill and we had no one to support us.

Cancer treatment affects existing motherhood identity, but it also changes future plans about motherhood. One of the major concerns of this change is the fear of cancer's recurrence or its fatal end. Participants, who earlier had plans to have one more children started to doubt about it because they do not know for sure that they will survive long enough to care them. Additionally, and more dramatically, one of the most severe side effects of breast cancer is experienced in fertility by severe impacts of chemotherapy as shutting down ovaries of patients and threw them into medically induced menopause. Pink (34, married with 1 child, informal sector) expressed her feelings as follows:

> During my chemotherapy, doctors put me into menopauses. Before my cancer, we were planning one more child. But now, I cannot have. Most probably, I will stay in menopause after that. So getting pregnant is like a dream for me and my daughter thinks she will have a sister in three years. I see my mistakes. I see them now. I worked so hard and now I will not have any children. The consequence is very tough. Not for me, for my daughter. How can I defend myself against my daughter when she finds out that she will never have a sister?

Thus, younger women with breast cancer face more dramatic effects on their motherhood. Reduced fertility and also uncertainty of future plans make it more difficult to continue their motherhood identity. Actually a study conducted in Australia showed that women without children described a distressing grief about lost fertility (Kirkman, Winship, Stern, Neil, Mann & Fisher, 2014). Therefore, breast cancer, fertility and reproductive health are interwoven in varied ways, which can have short and long-term psychological, physical and familial consequences.

Lastly, it should be noted that not only the relationships with spouses and children, but also the relationships with parents, siblings and other relatives get affected by this process. Indeed, parents are another significant care-providers during cancer treatment process. As a salient example, a participant with breast cancer defined her mother as her main caregiver. During her treatment process, participant's mother has moved in her daughter's house and provided her basic needs. This situation has not created a role change or any other kind of distress in familial relations, because as mentioned earlier, motherhood is a full time and non-ending care-giving process. Although the focus of my field study was not on siblings and other close relatives, I had also some cases regarding sibling caregivers. Indeed, in many cases, siblings can be responsible for a care of cancer patient. However, whether they would be main caregiver or not, breast cancer patients still expect their support. For instance, a participant complained about her sister's ignorance about her care needs. Apart from this, I do not have any precise example that can represent patients' perspective on this issue. However, below I will try to analyze the perspective of sibling-caregivers regarding this issue.

5. 4. 2. Caregivers' Experiences with Familial Impacts of Breast Cancer

Family members try to significantly change their roles in the family to accommodate the care-giving demands of women with breast cancer. Although deficient supportive systems in health care leads to rising participation of family members in caring for the ill member, little attention has been directed toward the needs of family members or the impact of the cancer on their lives. In this chapter the impact of the cancer on the family members will be analyzed and specific familial changes will be identified in caregivers' perspective.

As Rolland (1994) has discussed, chronic illnesses affect family functioning and multigenerational patterns. Chronic illnesses might arise for several times in the same family. Family members can be the main responsible for more than one patient. Each time, families might generate different adaptation levels and coping strategies according to characteristic of illnesses and patients and care needs. Each disease that confronts a family yields diverse caregiver roles. Some caregiver participants have mentioned their caregiver history as a repeating pattern. For instance, some participants were responsible for the care of an elderly parent or an ill mother-in-law earlier. Their new care-giving responsibilities create huge changes in their previous care-giving role. In some cases, they try to balance these both caregiver roles at the same time. But in most circumstances, caregivers try to make new regulations. For example, Brown (Man, 55, Husband, Caregiver) noted that he was formerly responsible for caring his elderly father-in-law. After the diagnosis of his wife, they made a huge change in their inner dynamics of family. They have sent their father to his sister-in-law's home. He said that "We heard that my wife had a cancer. But my father in law who is 90 years old was living with us. Then we decided to take him to my wife's sister. Although my wife didn't want to leave her father, she accepted it because her illness was more important."

Thus, it is obvious that the increase in care needs of women with breast cancer creates dramatic changes in each family member's life. If there is no other relative willing to take care of elderly or ill member in need, current caregiver tries to generate new coping strategies when a new patient comes out. Being responsible for more than one patient at the same time generate double burden on them. In the lack of professional support systems in the place, families try to undertake all care needs at the same time. It is a well-known fact that both elderly care and cancer care are seen as moral obligations in Turkey. Therefore, participants try to hide the burden they faced at first when they were asked. But then, they could have talked about their burden and strain due to increased care responsibilities. Indeed, after talking about their responsibilities, caregiver participants started to express their problems and complain. For example, after talking about how he handled all care activities for his mother, Beige (Man, 39, Son, Caregiver) expressed his problems encountered during this process as follows:

> My mother in law is living with us she has Alzheimer and had a stroke. It is not easy to carry a patient who cannot move from service to another service. Moreover she broke her knee. Think about it; I am carrying a patient with Alzheimer and broken knee from stretcher to x-ray table. I think this is not true. Now we hired an assistant for my mother in law. Actually we found a nursery house but we thought that she was not cared appropriately there. We had some doubts about her eating, cleaning and other needs. Thanks god my mom is not in her conditions.

Caring for more than one patients or elderly family members is different. However, being a caregiver of a cancer patient has also its own difficulties. In other words, caring for a cancer patients can be dramatic and stressful. Patients and other family members can suffer from depression, anxiety and stress. Although literature states that families that were able to act openly, express feelings directly, and solve problems effectively had lower levels of depression (Edwards & Clarke, 2004), in some cases a direct communication might hurt and upset family members. To be more precise, asking a family member to care a patient directly and without a prior discussion as an obligation might create bad feelings in the caregiver. For example, Brown (Man, 55, Husband, Caregiver), the husband of elderly women with advancing cancer noted that he felt compelled by the insistence of his son to act as her mother's primary caregiver despite the detrimental consequences to his physical and psychological health:

> After the first chemotherapy my son asked me to take care of my wife. He said that "Father, be patient for 5 years. None of us can help to our mother during this process. You have to handle all these responsibilities." 5 year was the maximum life expectancy for the patients in my wife's situation.

Care-giving to a wife can be challenging due to changed familial roles. It has been discussed for several times that female members face more burden on them due to their increased responsibilities in housework and child and elderly care. This is mainly because the traditional culture of family (Hacıalioğlu, Özer, Erdem & Erci, 2010). As discussed above, generally women are seen as the main caregiver and accepted as the main responsible for all housework, the new position of women under consideration create new paradigm in family. Male participants, who were previously not responsible for housework or cooking, start to feel a necessity to cope with these needs after the diagnosis. In some cases husband caregivers see their new role as a payback for his wife's prior labors. This was expressed by Ivory (Man, 49, Husband, Caregiver) as follows:

> While I was working, my wife used to take care of me very well. Every morning she used to prepare my outfit including my socks. This is so important for me. Not even for a day she complained or made a face. She supported me in my economic and emotional problems. Of course I will take care of her, in such a time.

When there is a husband willing to undertake care responsibilities, he mainly takes the economic and transportation needs. In most cases, physical and emotional cares are not provided by the male family members. Although the main caregiver is seen and accepted as the husband of the patient, daily personal care needs of women, such as medical dressing, bath, and house cleaning and cooking are generally undertaken by daughters or other female relatives. If there is no one to take these responsibilities, a professional helper is hired, if it is economically affordable. In other situations, male family members reluctantly try to cope with these expectations and needs. Thus, gendered division of labor is even sustained during cancer treatment process.

It is a controversial issue who will be responsible for which are need. Therefore, in the following pages, the emphasis will be put on negotiations of the care responsibilities among family members. Division of care can be arranged after a long negotiation process. This negotiation, as a common decision, can be made after reasonable discussion sessions. But in some conditions, this negotiation may yield disagreement and conflict among family members. Some members narrated that they undertake cumbersome burden while other members did not. This inequality between family members might end up with long-lasting antagonisms. During interviews, this form of negative negotiation is found between siblings when there is a care need of a parent. Sibling negotiation about who will be responsible for care needs is made according to different criteria, such as age, work life, socioeconomic conditions, living arrangements and also willingness of the family member. Participants referred to almost all of these criteria in justifying their decisions and actions in relation to care responsibilities. The influence of gender on the division of responsibility among siblings is another controversial issue, because sons and daughters provide different care needs. My results show parallelism with previous studies on this issue. Actually, gendered responsibilities are seen as reproducing the gender inequalities during the cancer treatment process (Hequembourg & Brallier, 2005).

Decision of who will be the main health care proxy may also be taken without any prior discussions. In some families, a family member directly undertakes this role without questioning. When there is a family member who is willing and talented to care-giving, negotiation might be skipped and the member directly gets his or her role as the main caregiver. As can be seen from the quotation below, when a family member is the only responsible for the care needs of a cancer patient, she generates different legitimation for her situation and other family members' lack of responsibilities:

> I think I am suitable for it. No matter who does it, I would be always curious. I would like to control the situation. I think the reason might be the method of our getting raised. My mother attributed me a mission. I am the bigger sister in our family. I have some responsibilities. Additionally, I am not irrational, I never make anything that I am not sure. My bigger brother cannot do it. My younger brother has a child and wife. They cannot manage all these responsibilities. My sister is psychologically fragile, cannot face these responsibilities. But I can do it. My house is near here, I rented it by thinking these needs. My daughter is not a child anymore. It did not matter while she was younger too. But I never question my responsibilities. No, never. I never ask about it. (Crimson, Woman, 51, Upper sister, Caregiver)

As the incidence of women with breast cancer increases, families are faced with multi-faceted decisions about care-giving for ill members. As revealed by the interviews, female family members like daughters and sisters often take on more stressful and energy-consuming care-giving responsibilities with varying levels of help from other family members. This fact also shows the unequal distribution of care-giving activities among family members. Independent from the distribution of care-giving activities among family members, it is certain that cancer treatment process change family as a whole and also creates huge changes in familial relations. Therefore, families with cancer patients tremendously need professional support to overcome troubles of cancer treatment process.

5. 5. Living with Institutional Deficiencies

In Turkey, cancer control generally focuses on a narrow field including cancer registry, prevention, screening, early diagnosis, and cancer treatment. Although these priorities help to supply the basic care needs, health system in Turkey lacks the quality of care dimension. The result of this lack has been discussed in previous parts as physical, psychological, economic and familial impact of breast cancer. However, there are also huge deficiencies in institutional and governmental regulations and practices. Thus, in this part, experiences, needs and expectations of women with breast cancer and caregivers regarding institutional deficiencies will be discussed. In-depth interviews conducted with patients, caregivers and experts will provide a basis for understanding of these lacks. Stated expectations from the government and institutions during the interviews were quite similar for patients, caregivers and experts (oncologist, social worker, oncology nurse and psycho-oncologist). Therefore, in-depth interviews of these three actors will be analyzed under the same headings. These heading will be namely deficiencies in screening, deficiencies in knowledge, deficiencies in human resources, deficiencies in care facilities and deficiencies in regulations.

5. 5. 1. Deficiencies in Screening

Breast cancer can be diagnosed through several techniques. Some of them, like mammography, screening, self-testing, provide an early detection (Etzioni, et al., 2003). However, in the lack of efficient screening services provided by the government, breast tumor can be found in its late stages. As discussed and exemplified for several times in the literature, late discovery of tumors can significantly reduce survival chances of patients. The semi-structured in depth interviews have also indicated that breast tumor is not generally discovered at routine screening mammography. Patients, generally, discover a palpable lump on their own and therefore seek a diagnostic testing. Unfortunately most participants discovered their tumor by chance, and in the late stages.

As discussed in previous chapter, the recent regulations in the Health Transformation program, aimed to increase the population screening rates by organizing breast cancer screening every 2 years from the age of 40. Actually, to provide inclusive screening techniques to every individual, the government has started to found Cancer Early Diagnosis Screening and Training Centers (Kanser Erken Teşhis ve Tedavi Merkezi – KETEM in Turkish) in each city to offer population based screening and public training programs about different kinds of cancers free of charge. The KETEMs have developed new techniques and programs in order to increase the screened population. But, still women above 40 are not screened regularly. One of the main reasons of this shortcoming is lack of knowledge and consciousness regarding the significance of early diagnosis of breast cancer. Moreover, women can feel anxiety and fear regarding positive result. Similarly, women can underestimate their risk of breast cancer. Actually, Turkey is in the increased risk group in terms of women' likelihood to underestimate their risk for breast cancer (Kartal, Özçakar, Hatipoğlu, Tan & Güldal, 2014). Unfortunately, the findings of this study also support this fact. Indeed, almost all participants realized their tumor by chance. On rare occasions, they found it through a tactile exploration. As adduced by Ivory (Man, 49, Husband, Caregiver), informative TV programs can encourage women to self-examination: "My mother saw a program on TV which advises to self-examination for breast cancer. She kept this recommendation, because she had some pain on her breast. Then she discovered a palpable lump and went to doctor."

Additionally, a study conducted in Turkey also verifies these results. Breast cancer symptoms are principally self-detected and palpable lump at breast is the most repeated symptom, followed by breast pain and skin changes (Özmen et al., 2015). Therefore, it would be safe to argue that several factors, mainly related to health-care systems and patients' psychological and behavioral characteristics, determine delay in diagnosis and treatment. Thus, inclusive and nation-wide regulations to increase in cancer awareness among women and organized screening programs should be generated.

5. 5. 2. Deficiencies in Knowledge

Lack of knowledge about breast cancer continues after the diagnosis as well. It was mentioned by patients and caregivers that lack of knowledge regarding diagnosis and treatment process have a huge impact on their experiences. My in-depth interviews indicates that common information needs include healthcare services, tests, treatment options, medication, side effects of treatments, chance of survival and progression of the disease. To overcome this lack of knowledge, patients and family members access diverse information resources to support them through cancer treatment process. While some participants stated that they used booklets given from the hospital about side effects and to-do-lists regarding treatment process, some others mentioned they have never been provided any source for knowledge. Lavender (55, divorced with 2 children, teacher) said that: “When I come here for my first chemo, they gave me a booklet including a to do list for me. For instance, eat fish once a week. Never eat grapefruit. What will happen to you? What are the side effects of the chemo? This booklet was a life saver.”

However, it is a well-known fact that a patient or caregiver who adequately understood the disease and care options will be able to reach effective decision making regarding the process. For instance, some patients, who are old or uneducated, can feel the process as out of control. In these cases, family members try to learn more about the process just to be sure everything is accurate and under control. This also creates an additional burden on family members who try to provide necessary basic care treatments. For instance, Beige (Man, 39, Son, Caregiver) mentioned her mothers’ age as a knowledge-limiting condition which forces him to be ready in all doctor appointments: “Our patient is old. She can misunderstand the words of doctors. So I want to be with her to check all the steps. I made a huge research on this issue.”

When patients and caregivers feel their needs for knowledge is unmet by hospital personnel, they try to reach necessary information by using internet. In some cases, patients and family members think that internet provides more useful and valuable knowledge than booklets. Thus, it is possible to argue that Internet is an effective tool of information in cancer field. However, in the in-depth interviews, participants have also referred internet as providing misinformation. Actually, they are not totally wrong, because there are lots of information disseminated by public and private institutions and actors. Thus, sometimes it is so difficult to reach clear and adequate information. For instance, a research conducted in Turkey showed that websites about cancer are mostly trying to sell products or services about cancer (Tekin, Kaya & Yazıcı, 2012). Thus, these websites can have a negative impact on both patients and family members by influencing their decisions. In some cases, they can change their treatment paths according to these misleading websites.

Another area of usage of Internet is to check out the test results. Some interviewees remarked that they use internet when they got the results of a test. Mostly, they do not want to wait until the next appointment, because intervals between doctor appointments can be very long. Nevertheless, in some cases, internet can mislead the researchers and provide low quality of information. Furthermore, it may influence adversely the relationship between patients and doctors. As shared by Gray (Man, 50, Husband, Caregiver), doctors can be found misleading, thus, he tries to double-check each word her wife's doctor:

> There is a pollution of information. It is almost impossible to reach the correct information. Doctors are under control of the drug company representatives. So they can direct us in a wrong way. So we have to research each step of cancer treatment. Internet can mislead you. I think the Ministry of Health should create some websites like Uzman TV, which would provide accurate information.

Another great concern during this process is not knowing who to ask questions. Side effects of treatments, eatable and non-eatable foods, treatment opportunities, alternative supplementations, hospital and doctor recommendations are main needs of patients and caregivers. For family members, there is a unique fear and lack of knowledge regarding their care-giving responsibilities. Similarly, according to the results of a previous study conducted with relatives of a cancer patient, fear about caring for the patient at home and lack of information were the problems most frequently identified (Hockley, Dunlop & Davies, 1988). This is also valid for this study. As noted by Gray (Man, 50, Husband, Caregiver), a family member can fear to cause damage in the patient's health by making a mistake due to lack of knowledge:

> The most difficult part of care-giving is the lack of information because there is no information for family who tries to help the cancer patient. Doctors mention just the basic points in three minutes. When you come back to home, and face details you feel so alone. How will it change your life? How should she eat? All other details are needed to be researched so we made a huge research on the internet.

5. 5. 3. Deficiencies in Human Resources

As already discussed, lack of knowledge can be rooted in poor communication with health professionals. Actually, communication problems appear since the beginning of diagnosis. Some patients do not want to hear all details about their illnesses due to mechanic and unemotional approaches of doctors and other health personnel. Actually, according to a study, they want to hear their life-changing illness from a polite person who can understand their deep fears and anxiety (Leydon et al., 2000). On the other hand, some participants stated that they do not want extensive information about their condition and treatment. Indeed, preferences of patients for information derive from the coping strategy or attitude they used in managing their cancer. Thus, most patients and caregivers described difficulties associated with the delivery of bad news and treatment plans that are not clearly defined by the oncologist/participant. The ways of how a doctor explains the diagnosis to the patient create a huge impact on patients' psychology and in some cases play a significant role in determining the treatment path. Also, he said that it is important to inform the patients about the whole process with proper words because doctors have to tell them about a life threatening disease. If a doctor uses wrong words, a patient might not adopt the process. For instance, this oncologist/participant persuaded an old patient who refused an urgent mastectomy by using proper metaphors. As this example has shown, oncology is a field where each decision and step plays a life-changing role. Unfortunately, formal medical training mostly does not include communication skills courses for oncologists or cancer nurses. Similarly, the results of a previous study conducted with oncologists shows that insufficient training in communication skills is a major factor contributing to oncologist's own stress, lack of job satisfaction and emotional collapse (Fallowfield & Jenkins, 1999). As said by Violet (43, married with 2 children, retired) effective communication skills create important differences in health care outcomes: "My doctor has an interesting personality. He uses metaphors, meditation and yoga. I accepted my illness thanks to these supportive techniques"

Besides communication skills of doctors, behaviors during the on-going treatment are among the most important dimensions of doctor–patient communication. Doctors become the most important person in lives of cancer patient; by being the main authority determines everything in treatment procedure as well as in their private life. Women with breast cancer need to trust her oncologist in every sense to apply everything s/he says. Thus, an oncologist should spend an adequate time, labor and effort for each patient and examine her condition accordingly. An oncologist should avoid making general assumptions and wrong decisions. And moreover, a doctor should give information in a way that patients could understand properly and would help to reduce anxiety and depression. A wrong behavior or short time interval in a doctor interview might result in wrong diagnosis. Pink (34, married with 1 child, informal sector) said that: "My first doctor was awful. He put a glance on my results and said that I have nothing. We felt that he was trying to get rid of us. Then I went to another doctor who found out my cancer."

Nurses, doctors and other personnel play a huge role in treatment experiences of patients and caregivers. Most participants shared some complaints about hospital personnel and mentioned how their treatment process has interrupted due to actions of healthcare personnels. Difficulties in communication with hospital staff have been identified as potentially stressful for families. For instance, White (Woman, 25, Daughter, Caregiver) explained a huge misunderstanding and rude behaviors of doctors and nurses which bring out an interruption in her mother's treatment: "Doctors and other medical personnel are not good at communication with patients. Most of the doctors are rude and impolite. Now we are in a terrible situation because nurses made a huge mistake and now we have to go back to hospital again."

This problem and many others could have been overcome by supporting the patient and health care proxy by listening to them, accepting their emotions and informing them in detail. Therewith, they can express a sense of security to the women and help them to maintain the ability to deal with the necessary procedures. The experience of the patient might be determined by several factors, such as respecting to dignity and autonomy of patients and also how the patient is treated as a person. Actually, a study on this issue has also showed the importance of healthcare personnel. Patients are affected by the feelings whether personnel responds sympathetically to their pain, anxiety and distress (Purushotham, Cornwell, Burton, Stewart & Sullivan, 2013). Take chemotherapy nurses as an example. Women with breast cancer spend hours in chemotherapy. During this time, nurses are the main care providers of this treatment. Orchid (45, married with two children, formal sector) mentioned how nurses treat patients and their behaviors' impacts on patients:

> Patients are treated like sheep in a slaughter house. Chemotherapy in hospital is like waiting for a death. You should drink water all the time during chemo and eventually you need to use toilets. But you should wait for a nurse to go there. If she is in a good mood, she helps you to go to the toilet. But if she is angry, she yells at you by saying "Are you the only one here? You should wait. Look, everybody is waiting." We were waiting for that nurse's smile but she treated us like a dog. In radiotherapy, we wait for long hours. There is no standard time. We wait for the hospital personal's comfort. If you cannot rotate your body on your own, nurse yells "Come turn this to other side". We were all waiting in the same room. We all saw each other's life, breakdowns, crying… Another problem is radiologist's problem. It is so hard getting naked and lying on a stretcher in front of a man. You should do whatever he says. You lose your identity. He says "Get naked" and you get naked. And you don't know if this man is a pervert or not. You don't know his feelings. It is very horrible.

5. 5. 4. Deficiencies in Care Facilities

In some cases, healthcare personnel might behave helpful and polite to patients and caregivers, yet hospitals might still lack necessary structure. In the interviews, it was obvious that cancer care settings have huge lacks in terms of services, infrastructure and equipment which can adversely affect wellbeing of patients and caregivers. Firstly, hospitals do not have some basic services necessary for a holistic care. For instance, as mentioned by the oncology nurse I have interviewed, psychological services are mostly ignored in oncology services, however patients and families need regular consultations. Second, infrastructure of hospitals is not enough or needs revision. For example, the oncology nurse/participant stated that most hospitals cannot meet the demands of cancer patients. In other words, they do not have enough beds or treatment rooms. Overcrowded hospitals lead to long waiting intervals for patients. Women with breast cancer, who are already tired and fatigue due to severe side effects of the treatment process, can wait for long hours due to this lack. What is worse, in some hospitals there are no social areas where patents and their caregivers can wait. This is an important deficiency because, as a study has already shown, relaxing before and after treatment diminishes emotional stress and anxiety (Burish & Lyles, 1981). This was also clearly put by Magenta (43, married, no child, housewife), who had negative experiences due to long waiting intervals: "At hospital, there are problems too. You have to wait for hours even for a blood test. And you should wait as hungry as you will give blood. Once I was blacked out while waiting. In radiotherapy, you live this every day. I cannot sleep at night by thinking all of these procedures."

And third, my interviews have shown that equipment used in examination and treatment are old, insufficient or already absent. Additionally, chemo and radiotherapy machines are not equally distributed among and within cities. For this reason, patients can be directed to different hospitals and/or cities. In latter cases, patients should travel to another city to find an appropriate treatment opportunity. As explained by the oncology nurse/participant, beds allocated for cancer patients are limited and do not meet the demand. Further, although she works at the biggest hospital of her region, there is no service to accommodate the patients and their caregivers coming from different cities through referral chain. She said that families leave their home early in the morning and sometimes have to lodge in their cars parked in the hospital yard. Lodging in these places might create vital health problems for women with breast cancer due to unhygienic conditions. Moreover, quality of lives of these families is also a controversial issue in these healthcare units.

Nevertheless, hospitals should be places where hygienic conditions should be kept on optimum. Especially diseases like cancer, in which immune system of patients are indefensible to any kind of infectious attack, necessitates highly hygienic environment. During chemotherapy, patients take treatment through established vascular access, which leave their bodies unprotected to attacks of any kind of virus or microorganisms. Similarly, radiotherapy patients are subjected to open burnt skins, thus, they can easily catch an infection. Health-care associated infection might result in permanent damages and fatal consequences. During interviews, none of the participants said they got any infections throughout treatment process, yet all of them had such a fear. Indeed current health care facilities bolster this fear. For instance, a participant said that their chemotherapy unit was locked for a long time due to unhygienic conditions. Azure (54, married with 2 children, retired) also expressed her negative experiences in hospitals: "Hospitals should be more hygienic. Take chemotherapy stretcher as an example. One woman gets up and another one lies down. Cleaning is conducted when patient gets her treatment and everywhere becomes dusty. But we should stay in hygienic conditions."

To overcome these deficiencies, each health care setting should try to improve their infrastructure and services in an evidence-based approach. However, hospitals do not try to evaluate their infrastructure by applying assessment tests through which they can collect feedbacks from patients and family members regarding their treatment process. An assessment which aims to detect lacks and deficiencies in the service quality can improve infrastructures of hospitals. Also, to improve service quality, there should be some efforts to compare the service quality of health care organizations on the basis of patient satisfaction data. These examinations can measure satisfaction scores of patients and family members and the institutional characteristics of the health care organization

(Young, Meterko & Desai, 2000). However, in Turkey, assessments of hospitals are not adequate and they are based on quantitative standards such as number of beds, doctors, nurses and patients.

5. 5. 5. Deficiencies in Regulations

As discussed above, Health Transformation Program in Turkey has brought important changes for cancer patients. "Social Security Institution Health Implementation Communiqué" announced that cancer treatment is free of charge for all citizens in Turkey and all standard treatments are available in the country (Republic of Turkey Ministry of Health Department of Cancer Control, 2010). Once diagnosed with cancer, patients who are covered by the insurance can get treatment from public and private facilities without any out-of-pocket payments (Tatar & Tatar, 2010). Although cancer treatment expenditures are widely covered in Turkey, there are still problems associated with the general accessibility of the health care system. Each cancer patient should be registered in the health care system and follow specific steps of cancer treatment process to be qualified for payments. Moreover, these are not enough for access to health care, because there are some complications and deficiencies in health system due to long waiting lists, complicated referral systems, bed and equipment capacities, health care human resources and infrastructures like food and psychological services. Actually, the recent National Cancer Control Program has generated a future plan in cancer care in order to solve these shortages in the health system.

My field study has showed that one of the most important problems regarding health care is difference between private and public hospitals. In some cases, private hospitals could demand additional payments from cancer patients. But, the recent regulation issued them strong punishments and each patient can apply to Social Security Central Directorate of Health to demand their payment back. However, this procedure is not known by most people and they do not know their basic rights. Other problems of health system in Turkey are long waiting lists, low quality services and access problems. Unfortunately, in Turkey optimal treatment is not equally available across regions.

As already said above, women with breast cancer can try to get treatment from other hospitals or cities. Indeed, the recent health regulation recognizes right of patients to select their hospitals and doctors. But, in reality, it is not so easy. In order to change the city or hospital, a patient must follow a regular referral system and written formal prescriptions. For them, this often means to spend considerable time in long queues. However, in some cases patients can demand to change their hospital or city due to personal reasons. In such case, changing a city can create major problems for patients in that they must bring their treatment files to the new hospital or city. What is significant, although cancer registration system is presented as the most important aspect of current health system, it does not have a national information system that can transfer health files of patients among care facilities. The case of Green (51, married with 2 children, retired) who had two different cancer treatments due to metastatic cancer and changed her city between treatments can explain what I am arguing.

> Between my two cancers, I moved out to another city. Turkish Health System works correctly if you have all of your treatments in the same hospital. If you change city, you face new troubles. For instance, my doctors wanted to learn more about my first treatment. They should compare my illness with the previous one, but the information regarding my previous cancer was in the other hospital. They didn't want to send information file to my new doctors, they asked me to go there.

Thus, cancer registration system should be reorganized to work more efficiently in order to diminish troubles of patients who want to change hospitals and/or cities.

5. 5. 6. Deficiencies in After Treatment Process

Even though a patient can successfully complete all these treatment steps, there remains another gap in the health system. The treatment process ends and women with breast cancer turn into a survivor. Needs of breast cancer survivors have generally been neglected in health and social policies. Breast cancer survivors continue to experience physical, economic and psychological morbidity after their treatment. While patients can find emotional support to adjust their lives to this illness and their new identities during treatment process, they mostly feel alone and isolated after the treatment process. Some participants, treatments of whom have finished, mentioned some post-treatment needs such as rehabilitation, well-being actions and reintegration into the workforce. As mentioned by Thistle (46, single, no child, informal sector), patients encounter a variety of problems after discharge from hospital:

> Nobody cares what you live after treatment but it is so hard. There is a huge gap after treatment, because you live with your fears. What if it repeats? How should I live now? It is a big loneliness. During your treatment, you see your doctor every day. Nurses support you. But after treatment, you are alone and nobody supports you.

The experience of loneliness for women after cancer treatment process may cause depression and anxiety. As discussed above, most of the participants have a fear of reoccurrence or spread of their cancer, however, they have no one to ask their questions. Almost all survivors referred how they felt alone in their changed perception of identity and future plans. Therefore, post-treatment support can be crucial for some cancer survivors. This is mainly because cancer can be experienced again by the same woman for several times, and they can judge their future by their prior experiences. They mostly feel that their cancer was over but then they are afraid of living everything again. Due to their prior experiences and the feeling of “everything was for nothing” can make them hopeless about their future treatment process. As Green (51, married with 2 children, retired) said:

> This is my third cancer. But my son says that you cannot handle a third chemo. Actually now I think I can avoid medical treatments and start an alternative medicine. Cancer made me a different person. Two years ago I could never think about becoming a person like that. Now I hope for help in things I have never thought to try before.

All in all, institutional deficiencies have a huge impact on quality of life and care of women with breast cancer and caregivers. By improving the current health services and also developing necessary regulations, patients and caregivers would experience cancer treatment process in a more organized and well-structured atmosphere.

CHAPTER VI

CONCLUSION

Turkish welfare regime, generally classified as a version of the Southern European Conservative welfare regime, based mainly on family and kinship relations and solidarity networks with the minimum role of state in social policy, has undergone a salient transformation within the last three decades. There are at least three aspects of this transformation. First, Turkey has experienced tremendous changes in its demographical composition. More specifically, the rate of elderly people is continuously rising due to gradual improvements in health conditions and increase in the average life span (Arun, 2014). Second, as discussed in the fourth chapter, since 2003, as a result of neo-liberal restructuring, Turkey has introduced a series of major changes in its health system through Health Transformation Program and has also inaugurated some arrangements about cancer. Last but not least, as a result of massive internal migration, nowadays, the majority of population in Turkey is living in urban areas (Yilmaz, 2015). One of the most important consequences of urbanization is the emergence of different family types.

Despite of diversification in the types of family and changes in the familial relations and roles, almost all types of care are still largely undertaken by family members (Hacıalioğlu, Özer, Erdem & Erci, 2010). Furthermore, this is supported by health and social policy regulations that still assume the family as the chief actor in the welfare regime of Turkey. However, as analyzed above, in the treatment of breast cancer that needs long-term, complex and intense care, the role of family is not straightforward. Indeed, family can play a positive or negative role. In many cases, family can be the source of affection and support. But, there are also cases in which family members can neglect the needs of cancer patients. What is more, some patients are not married and/or do not have close family members. Therefore, it would be wrong to assume that every family can offer all kinds of support and care to its members with breast cancer. Indeed, in some cases, socio-economic and socio-psychological problems of women with breast cancer cannot be solved in the domain of family. Thus, one can argue that this is where the family based social and health policies are not well-functioning.

As already said, like other types, breast cancer needs long-term, complex and intense care. Actually, as discussed earlier, breast cancer has its own uniqueness due to the location of tumor and side effects of its treatment. Although there are important advancements in techniques of cancer treatment and early diagnosis, in many cases the duration of breast cancer treatment is long and unpredictable. Furthermore, during the treatment process, patients as well as caregivers encounter multifaceted impacts in the domains of physical, psychological, economic and familial, issues. Also, breast cancer patient needs long-term and multi-dimensional care. This means that both cancer treatment and care are long and multi-dimensional processes. Thus, in the cancer treatment and care there is a huge need for a holistic approach that considers social and psychological needs of patients and incorporate socio-cultural characteristics of patients to its program. More specifically, the holistic approach sees patient as a whole and takes caregivers and family members of patients into consideration. It tries not only to treat the illness but also to manage the whole process of the treatment.

This thesis has three main parts that presents findings of my research. After the introduction and method chapters, in the third chapter, I focused on the ongoing practices regarding cancer, including discussions on cancer treatment and the existing policies of different countries which are classified into four groups in terms of their place in the Human Development Index. Second, I briefly discussed the current situation of health and cancer policies in Turkey with special focuses on the recent changes in health transformation program and transformation of cancer policies. And third, I analyzed the findings of my field study about experiences and expectations of patients, caregivers and experts from different socioeconomic and socio-cultural backgrounds in order to develop evidence-based and inclusive policy recommendations.

Now, I would like to recommend applicable and practical health and social policy regulations based on evidence gathered from my field study and analysis of ongoing cancer policies from different regions of the world. Before presenting my recommendations, it would be helpful to give a brief description of evidence-based approach. First, it tries to develop policy recommendations appropriate for cultural, economic, social and regional structure of a country. For instance, while a low-income country would like to increase its poor cancer survival, another country could try to diminish its culture-induced treatment biases. Second, cancer care based on evidence-based health and social policies aims to ensure a high quality of care to all patients and also to caregivers, because this policy type takes the real needs and expectations of the stakeholders into consideration. In other words, evidence-based policy practices are highly concerned with the experiences of the real actors. This approach is necessary and would be very helpful especially when dealing with life threatening issues like cancer or other chronic illnesses. Thus, I would like to investigate the possibility of developing evidence-based and inclusive health-based social policies to enhance the quality of life and care of women with breast cancer and of their caregivers. In what follows, I would like to present my evidence-based health and social policy recommendations.

1) One of the most important findings of this thesis is the lack of personalized treatment. There are more than 100 different types of cancer (Levine, 1993). But, in Turkey health system generally treats each type as similar and applies almost same treatment procedures. Furthermore, it does not give sufficient attention to the stages of cancer. However, patients with advance cancer mostly need special arrangements and additional supplements that are unmet by the current health system. Thus, health system in Turkey should generate multidisciplinary teams to treat each cancer differently by adopting a holistic approach.

2) As noted above, almost all breast cancer patients have severe physical difficulties during the treatment process. They need physical support to sustain their everyday life and their personal hygiene. As revealed by this study, caregivers and other family members

also need physical help. Thus, one can recommend a regular assistance for tangible needs such as housework and cooking.

3) As noted above, another striking deficiency about cancer care is transportation. This problem has two dimensions. First, women with breast cancer face difficulties in finding an appropriate transportation to access treatment facilities. Especially women who do not have personal cars have difficulties in public transportation. And second, due to unequal distribution of health services in terms of hospitals, equipment and human resources, some patients need to change their cities for treatment. In the latter situation, they should overcome long and complicated referral system and prove their eligibility for partial payment. Thus, there is a huge need for nationwide transportation system for cancer patients.

4) Both patients and caregivers experience difficulties in their working lives. Women with breast cancer working in informal sector have no legal protection during and after the treatment process. Similarly, caregivers have great troubles in balancing their work and care-giving responsibilities. Therefore, there is a huge need for legal arrangements that regulate working lives of both patients and caregivers in accordance with the treatment process.

5) There is a great deficiency in psycho-oncological support for patients and caregivers. Indeed, in Turkey psycho-oncology is not a well-developed field. The development of this field is an urgent necessity, because both patients and caregivers need psycho-oncological supports. This can decrease their psychological strains created by the cancer treatment process. Furthermore, each cancer treatment unit should have a multidisciplinary team including at least one psycho-oncologist.

6) Families are also affected from the entire process. Families should utilize their financial, emotional and physical resources to handle cancer care, but they differ from each other in terms of their resources and coping strategies. The unequal distribution of resources among families results in health care disparities and inequalities in cancer care.

Moreover, care-giving in family is not a static process. In other words, it needs a kind of labor division among family members. Furthermore, roles of family members in cancer care would change in accordance with their specific conditions and willingness as well as needs and expectations of patients. This dynamic nature of cancer care is not adequately taken into consideration by the current social policy regulations which assume that care-giving activities are undertaken by only one family member throughout all process. Therefore, health and social policy arrangements and regulations should take inter- and intra-familial differences into account.

7) As noted above, family members face some psychological troubles during cancer treatment process. Furthermore, they have to change their everyday life routines. Indeed, some of them are unable to meet their own health and social needs. Indeed, many complain about not having time for themselves and loss of their independency. Therefore, one can recommend regular familial therapies that can diminish negative psychological impacts of cancer treatment and care on family members.

8) Another deficiency concerning institutional regulations is the attitude of oncology professionals. Indeed, as noted in the previous chapter, both patients and caregivers complain harsh and unconcerned attitudes of health care professionals. Therefore, there should be a compulsory training program to develop communication skills of oncology professionals. This program can help them to use proper languages and attitudes towards patients and caregivers and to understand their emotions and concerns.

9) Moreover, there are great inequalities among hospitals, cities and regions in terms of equipment, hospital capacities and human resources. These inequalities directly influence the quality of cancer care. Therefore, the Ministry of Health should try to eliminate these inequalities in order to increase both accessibility and quality of cancer care.

10) As revealed by this study, both patients and caregivers do not have sufficient and necessary knowledge about cancer and cancer treatment process. The Ministry of Health

should produce new informative channels like booklets, websites, free of charge phone services and T.V. programs in order to develop and improve its information system.

11) As discussed above, patients encounter great troubles when they changed hospital and city. Establishment of a national database, including all necessary information about the treatment process, can make it easier to follow treatment process in different hospitals and cities.

12) As shown by this study, it is almost impossible to reach comparable data about health and social policies of different countries concerning cancer treatment and care. Establishment of an international database that includes not only basic cancer statistics but also social policy regulations about cancer can enable us to compare differences and similarities among countries. This would help countries to learn from other countries practices and to exchange information about cancer.

13) Needs of cancer patients do not end when cancer treatment is completed. Even after the cancer treatment process, physical and psychological impacts of cancer on patients would still continue to shape their life routines, priorities and personalities. Thus, there must be continuous therapies and follow-up plans for patients in order to facilitate their adjustment to the new phase.

14) What is striking, social workers play a very limited role in the current health system. The main reason of this is that in Turkey social work is not well-structured and well-established theoretical and professional field. However, social workers can help cancer patients and their caregivers to cope with the side-effects of the cancer treatment and to improve their well-beings. Therefore, social workers should take a more active role in the cancer treatment and they must be included in multidisciplinary teams. This would also improve the psychosocial dimension of care.

As a final point, it must be emphasized that all these health and social policy recommendations should consider socio-cultural and economic differences of patients and family members and aim to diminish the unequal and discriminatory regulations.

Recommendations with this perspective can increase the quality of life and care of patients, caregivers and other family members. Furthermore, these recommendations can play a key role in the improvement of formal and informal care systems that is mainly based on family. In turn, this can lead some changes in internalized gender and familial roles in cancer care. Lastly, these recommendations can contribute to raise public awareness about early screening, treatment opportunities, healthy lifestyles, and preventive measures, and rights of patients and caregivers.

Based on the findings of this thesis, it is possible to develop some topics for further research. As already noted, in Turkey, literature about needs, experiences and expectations of cancer patients and their caregivers is very limited in social science, except psychology. Therefore, there is a great need for further research about patients with different cancer types and stages and their caregivers, as well as their socio-economic conditions and troubles. As already shown, neither cancer patients nor caregivers are homogenous in terms of their socio-economic and socio-cultural characteristics, as well as their needs, problems and expectations. As a qualitative field study, I carried out in-depth interviews with relatively small group of patients, caregivers and experts. New qualitative studies in this area can bring new data and broaden our perspectives. Additionally, in this study main focus was on women with breast cancer. New studies that focus on male cancer patients would help us to have a better understanding of gender dimension of cancer treatment and care. More specifically, one should study the economic, physical, psychological and familial impacts of cancer when the patient is a male member of a family.

Steady rise in cancer incidences and chronic illnesses makes long term care an important issue for health systems and also families. However, in Turkey, there is a very limited literature about care. Therefore, there is a great need for new studies how care is handled and maintained by families. Indeed, while I was conducting in-depth interviews for my master thesis, I realized that although end of life well-being is an important part of the quality of life, there was no palliative care unit in Turkey, neither for cancer patients nor for elderly people. Only in July 2015, the Ministry of Health issued a regulation concerning palliative care units. Therefore, one can study palliative and elderly care and impacts of newly introduced palliative care regulations on families.

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APPENDICES

APPENDIX A: IN-DEPTH INTERVIEW QUESTIONS

DEMOGRAFİK SORULAR

1. Yaşınız
2. Eğitim Durumunuz
3. Mesleğiniz nedir?
4. Kaç yıllık evlisiniz?
5. Kaç çocuğunuz var ve yaşları kaç?
6. Sosyo-ekonomik durumunuzu nasıl tanımlarsınız?
7. Sağlık hizmetlerinde faydalandığınız özel veya genel sağlık sigortanız nedir?

TEŞHİS ÖNCESİ ZAMAN KULLANIMI

8. Teşhis konulmadan önce bakımından sorumlu olduğunuz birey/bireyler var mıydı? Var ise bakımları için neler yapıyordunuz, ne kadar süre ayırıyordunuz?
9. Teşhis konuşmadan önce ev içi işleri için ne kadar zaman ayırıyordunuz? Bu sorumlulukları yerine getirmek size bir zorluk teşkil ediyor muydu?
10. (Çalışıyor ise) Çalışma hayatınız ne kadar zamanınızı alıyordu? Mesleğinizde temel sorumluluklarınızdan bahseder misiniz?
11. Genel olarak günlük ve haftalık programınız nasıldı? Neye ne kadar zaman ayırıyordunuz?

TEDAVİ SÜRECİ

12. Hastalığınız ne zaman ve nasıl teşhis edildi?
13. Tedavi sürecinde nasıl ilerleyeceğinize nasıl karar verdiniz?
14. Tedavi sürecinde hangi yöntemleri kullandınız? (Kemoterapi, radyoterapi…)
15. Tedavi sürecinde hastane ve diğer kurumlara ulaşımınızı nasıl sağladınız? (toplu taşıma, özel araç, servisler…) Bu ulaşım yöntemi sizin için herhangi bir zorluk yarattı mı?
16. Tedavi süresinde karşılaştığınız güçlükler nelerdir?
17. Bu süreçte ortaya çıkan ihtiyaçlarınız oldu mu? Olduysa nelerdir? Nasıl karşılandılar?
18. Tedavi sürecinde aileniz tarafından karşılanan ihtiyaçlarınız nelerdir?
19. Tedavi sürecinde devlet tarafından karşılanan ihtiyaçlarınız nelerdir?
20. Tedavi sürecinde yakın çevreniz tarafından karşılanan ihtiyaçlarınız nelerdir?
21. Tedavi sürecinde komşular veya iş arkadaşlarınız tarafından karşılanan ihtiyaçlarınız nelerdir?

İŞ HAYATI

22. Hastalığınızın teşhisinden önce herhangi bir işte çalışıyor muydunuz?
23. Teşhis konulduktan sonra işinize devam ettiniz mi?
24. Tedavi sürecinde çalışma yaşantınızda değişiklikler oldu mu? (Çalışmanın bırakılması, ara verilmesi, sürenin azalması, evden çalışmak gibi)

25. (Süre azaldı veya evden çalışmaya geçildiyse) Tedavi süreci sonrasında eski çalışma şeklinize dönmeyi düşünüyor musunuz? Evetse herhangi bir güçlükle karşılaşacağınızı düşünüyor musunuz?

26. (Çalışmaya ara verdi veya bıraktıysa) Tedavi süreci sonlanınca iş hayatınıza dönmeyi planlıyor musunuz? Evet ise aynı işe mi yoksa farklı bir işe geçiş yapmayı mı düşünüyorsunuz?

27. (23. soru evetse) İş hayatınıza dönmek istediğinizde herhangi bir güçlükle karşılaşacağınızı düşünüyor musunuz? Evetse nelerdir?

28. (23. soru evetse) İş hayatınıza döndükten sonra herhangi bir güçlükle karşılaşacağınızı düşünüyor musunuz? Evetse nelerdir?

DUYGUSAL İLİŞKİLER

29. Hastalığınızın teşhisinden önce aile içi ilişkileriniz nasıldı?
30. Ailenizde sizden beklentiler nelerdi? Bu beklentilerin sizi zorladığı durumlar oluyor muydu?
31. Duygusal ilişkilerinizde herhangi bir değişiklik oldu mu? Olduysa kiminle olan ilişkinizde nasıl değişiklikler yaşandı?
32. Kişisel psikolojik durumunuzda değişiklikler oldu mu? Bu süreçte bir psikolojik destek aldınız mı?
33. Hastalığınızın teşhisi ve tedavi sürecinde duygusal açıdan destek alıyor musunuz?
34. Duygusal açıdan destek almaya ilişkin beklentilerinizi öğrenebilir miyim?

35. Bu süreç içerisinde yeni dahil olduğunuz destek grupları, topluluklar ya da arkadaşlıklar oldu mu?

36. (Evetse) Bu gruplardan nasıl haberdar oldunuz? Sizin hayatınızda nasıl bir etki yarattılar?

EV İÇİ İŞLERDE YAŞANAN DÖNÜŞÜM

37. Hastalığınızın teşhisinden önce ev içi işlerinizi nasıl tamamlıyordunuz? Bir yardım alıyor muydunuz yoksa tek sorumlu siz miydiniz?
38. Hastalığınızın teşhisinden önce ev içi işlerinin gerçekleştirilmesinde zorlanıyor muydunuz?
39. Teşhis konduktan sonra tedavi sürecinde ev içi işlerinin gerçekleştirilmesinde bir yardım alıyor musunuz? Sorumluluklarınızda bir değişim yaşandı mı? Nasıl?
40. Tedavi sürecinde yemek, temizlik ve çamaşır gibi ihtiyaçların yerine getirilmesinde değişiklikler yaşandı mı? (yemek içeriklerinin değişimi, temizlik malzemelerinin değişimi gibi) Evetse bu değişikliklere kim/kimler karar verdi, nasıl uygulanıyor?
41. Tedavi sürecinde evde genel anlamda değişiklikler yaşandı mı? (eşyaların düzeni, evcil hayvanlar, oda düzenlemesi, hanehalkı üyelerinin değişmesi gibi)
42. Temizlik, yemek, bulaşık ve çamaşır gibi işler bu süreçte kim/kimler tarafından gerçekleştiriliyor?
43. Varsa yaşanan değişim size kendinizi nasıl hissettiriyor?
44. Bu süreçte kim/kimler tarafından yardım alıyor, destek görüyorsunuz?
45. Kimler tarafından yardım almak ve destek görmek isterdiniz?

BAKIM İŞLERİ İLE İLGİLİ SORULAR

46. Hastalığınızın teşhisinden önce hane içerisinde bakım sorumluluğu sizde olan çocuk, yaşlı veya engelli bireyler var mıydı?
47. Bu kişi/kişilerin bakım hizmetlerini gerçekleştirirken yardım aldığınız kişi veya kurumlar var mıydı?
48. Bu bakım işlerini gerçekleştirmek size günlük hayatınızda bir zorluk teşkil ediyor muydu?

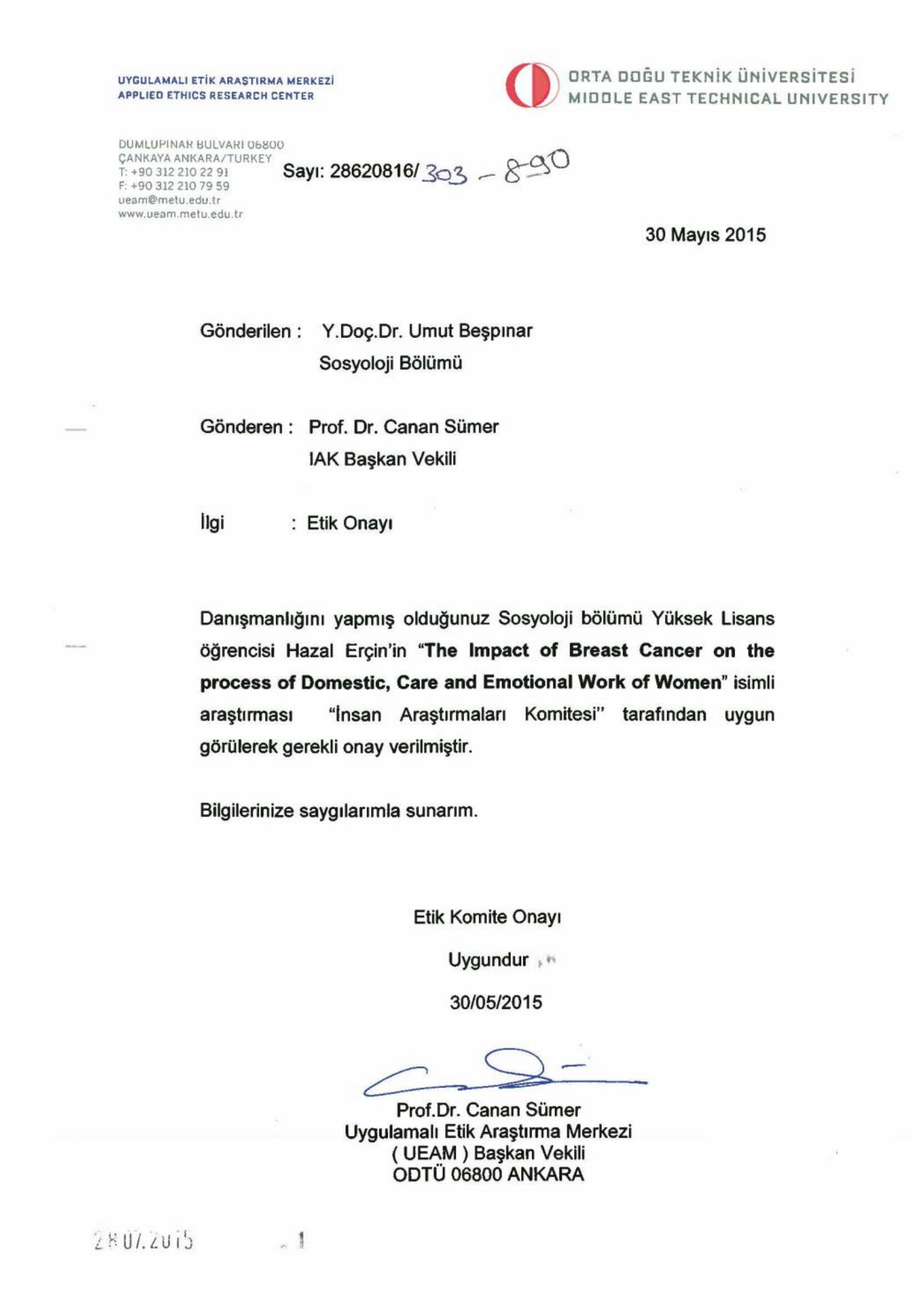
49. Hastalığınızın teşhisinden sonra bu bakım işlerinizde bir değişim meydana geldi mi?
50. Hastalığınızın tedavi sürecinde çocuk, yaşlı ve/veya engelli bireylerin bakım işlerini kim veya kimler tarafından gerçekleştiriliyor?
51. Bu dönüşüm size nasıl hissettiriyor?
52. Bu bakım işlerinin yerine getirilmesinde kimlerden nasıl destek almak isterdiniz?
53. Kişisel bakımınızda herhangi bir değişiklik gerekli oldu mu? Evetse nelerdir?
54. Kişisel bakımınızı yerine getirirken destek gördüğünüz kişi veya kurumlar var mı?

BEDEN - KENDİLİK ALGISI

55. Hastalığın teşhis edilmesi ve tedavi sürecinin başlamasından itibaren kendinizle ilgili düşünce ve duygularınızda bir değişiklik oldu mu?

- Ruhsal açıdan
- Bedensel açıdan
- Cinsel açıdan
- Anne olarak
- Eş olarak
- Kız çocuk olarak

APPENDIX B: METU ETHICAL COMITEE APPROVAL PAGE



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Gönderilen : Y.Doç.Dr. Umut Beşpınar
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Gönderen : Prof. Dr. Canan Sümer
IAK Başkan Vekili

İlgi : Etik Onayı

Danışmanlığını yapmış olduğunuz Sosyoloji bölümü Yüksek Lisans öğrencisi Hazal Erçin'in **"The Impact of Breast Cancer on the process of Domestic, Care and Emotional Work of Women"** isimli araştırması "İnsan Araştırmaları Komitesi" tarafından uygun görülerek gerekli onay verilmiştir.

Bilgilerinize saygılarımla sunarım.

Etik Komite Onayı

Uygundur

30/05/2015

Prof.Dr. Canan Sümer
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28.07.2015

APENDIX C: TURKISH SUMMARY

MEME KANSERİYLE YAŞAMAK: POLİTİKA PRATİKLERİ VE ÖNERİLERİ

Erçin, Hazal
Yüksek Lisans, Sosyal Politika Bölümü
Tez Yöneticisi: Doç. Dr. Fatma Umut Beşpınar

Bu tez, meme kanserli kadınların ve bakım sağlayan aile üyelerinin deneyimlerini, problemlerini ve ihtiyaçlarını anlamayı ve analiz etmeyi hedeflemektedir. Bu amaca yönelik olarak, farklı ülkelerin ve Türkiye'nin kanser ile alakalı güncel sağlık ve sosyal politika uygulamaları incelenmiş ve meme kanserli kadınların ve bakım sağlayanların ihtiyaç ve deneyimlerini anlamak için yarı yapılandırılmış derinlemesine mülakatlar gerçekleştirilmiştir. Ayrıca, tezin sonunda, saha çalışmasından elde edilen bulgulara ve farklı ülkelerin güncel kanser politikalarının analizine dayanarak, meme kanserli kadınların yaşam ve bakım kalitelerini iyileştirmeye yönelik kanıta dayalı sağlık ve sosyal politika önerilerinde bulunulacaktır.

İlk kısımda farklı ülkelerin kanser ile alakalı sağlık ve sosyal politika uygulamaları incelenmiştir. Bu ülkelerin politika uygulamalarını daha genel bir çerçeveden ele almak için İnsani Gelişmişlik İndeks puanları temel alınarak dört temel başlık altında gruplandırılmışlardır. Bu başlıklar çok yüksek, yüksek, orta ve düşük insani gelişmişlik gruplarıdır. İlk grup olan çok yüksek insani gelişmişlik grubundaki ülkelerin tamamına yakınında kanser tedavisine yönelik geliştirilmiş ve kapsayıcı altyapı ve insan kaynakları mevcuttur (Albreht, Jelenc, & Gorgojo, 2013). Bu ülkeler kanser hastalarının ve bakım sağlayan aile üyelerinin ihtiyaç ve isteklerini kapayacak sosyal politikalar düzenlemişlerdir. Ancak bu sosyal politikaların sunulmasını öngördüğü sosyal hizmetler genel olarak gelir ve geçim araçları yoklaması ile düzenlenmektedir (Atun, Ogawa, & Martin-Moreno, 2009). Bunlara örnek olarak Avrupa Birliği ülkelerinin bakım ve yaşam kalitesini artırmak için kanser hastalarına sundukları ulaşım hizmeti ve psikolojik destek servisleri gösterilebilir (Tyson, 2010; Borras & Prades, 2014). Bir diğer örnek olarak, Avustralya'nın ev işleri, yemek ve fiziksel değişimler konusunda düzenli destek veren ücretsiz programlar sunması verilebilir. Çok yüksek insani gelişmişlik grubundaki ülkelerin neredeyse tamamı meme kanserli kadınlar ve bakım sağlayan aile üyelerinin çalışma yaşamları hakkında koruyucu düzenlemeler geliştirmişlerdir (The Family and Medical Leave Act, 1993).

İkinci başlık olan Yüksek İnsani Gelişmişlik grubundaki ülkelerin kendilerine ait ulusal sağlık ve sigorta sistemleri bulunmaktadır ancak sağlık ve sigorta sistemleri farklı kapsama koşullarına ve pratiklerine sahiptirler (Gravena et al., 2013). Genel anlamda kanser teşhis ve tedavisine yönelik gerekli altyapıya ve insan kaynaklarına sahip olduklarını söylemek mümkündür. Fakat ülkeler içinde kanser hastalarına sunulan hizmetlerde bölgesel eşitsizlikler yaşanmaktadır. Bu ülkelerin temel eksiklikleri kanser ile alakalı toplumsal bilincin yeterince gelişmemiş olmasıdır (Asadzadeh, Broeders, Kiemeney & Verbeek, 2011). Bu bilinçsizlik kendisini tarama ve tedaviye başvurudaki düşük sayılarda göstermektedir. Kültürel, dini ve sosyal faktörlerin yarattığı bu bilinçsizlik teşhis ve tedavi oranlarına doğrudan yansımaktadır (Norsa'adah, Rahmah, Rampal & Knight, 2012).

Orta İnsani Gelişmişlik düzeyindeki ülkeler, kanser teşhis ve tedavisinde yetersiz hizmet sunmaktadırlar. Bu ülkeler hem sağlık merkezi, ekipmanı ve hizmeti sunumunda, hem de onkoloji insan kaynaklarında eksiklikler yaşamaktadırlar (Bray, Jemal, Grey, Ferlay & Forman, 2012). Bunun yanı sıra, bu gruptaki ülkeler tüm nüfusu kapsayan çok boyutlu bir kanser kayıt sisteminden de yoksundurlar. Tüm bu eksiklikler, meme kanseri teşhis ve tedavisi pratikleri üzerinde doğrudan ve olumsuz bir etki yaratmaktadır ve kanser genellikle son aşamalarında tespit edilebilmektedir (Hussain & Sullivan, 2013). Son grup olan Düşük İnsani Gelişmişlik düzeyindeki ülkeler, kanser teşhis ve tedavisine yönelik alt yapı ve insan kaynakları bakımında çok çarpıcı eksiklikler yaşamaktadırlar. Aynı zamanda kapsayıcı ve düzenli sağlık sigorta sistemlerinde de eksiklikler göze çarpmaktadır (Bridges et al., 2011). Ancak daha da önemlisi, bu ülkelerde bulaşıcı hastalıklar çok yaygın olduğu için, devletlerin sağlık düzenlemelerindeki öncelikleri meme kanserini kapsamamaktadır (Bray, Jemal, Grey, Ferlay & Forman, 2012). Bu sebeple meme kanserli kadınların ihtiyaçları çoğunlukla karşılanmamaktadır.

Türkiye yüksek insani gelişmişlik düzeyindedir ve genel olarak grubundaki diğer ülkelerin özelliklerini yansıtmaktadır. Aynı şekilde altyapı ve insan kaynaklarında bölgesel eşitsizlikler bulunmaktadır ve nüfusu meme kanseri hakkındaki yeterli bilince ulaşmamıştır. Türkiye'nin kansere yönelik sağlık ve sosyal politika düzenlemelerine bakıldığında Sağlıkta Dönüşüm Programı'nın büyük bir dönüşüm yarattığını görmek mümkündür (TC Sağlık Bakanlığı, 2007). Bu program sayesinde kanser hastaları, ameliyat, kemoterapi ve radyoterapi gibi temel tedavi hizmetleri için gereken ödemelerden muaf tutulmuşlardır (Başol & Işık, 2015). Aynı zamanda, tüm bölgelerde açılan Kanser Erken Teşhis Tedavi ve Eğitim Merkezleri 40 ve 69 yaş arası kadınlara her iki yılda bir ücretsiz kanser taraması hizmeti sunmaktadır. Bunların yanı sıra, Sağlıkta Dönüşüm programı ile aile hekimi uygulamasına başlanmıştır. Bu uygulama ile her hastaya düzenli görüştüğü bir aile hekimi atanması ile verimliliğin ve sürekliliğin artırılması, hastanelerdeki yoğunluğun da azaltılması hedeflenmiştir (Ergun & Ergun, 2010).

Tüm bu olumlu gelişmelere rağmen altyapı ve insan kaynaklarında Türkiye hala önemli eksiklikler yaşamaktadır. Sağlık hizmet ve kaynaklarının dağılımında hastaneler, şehirler ve bölgeler arasında önemli eşitsizlikler vardır (Kuter & Çakır, 2004). Aynı şekilde ülke genelinde tedavi için gerekli radyoloji ve kemoterapi teçhizatı eksikliği yaşanmaktadır (Erkoç & Yardım, 2011). Hastanelerin yatak sayısı yetersiz kalabilmektedir. Ve onkoloji uzman sayısı nüfusun ihtiyaçlarını karşılamanın çok gerisinde kalmaktadır. Özellikle radyolog sayısındaki eksiklikler hastaların gerekli tedaviye ulaşımında olumsuz etkiler yaratmaktadır (Sağlık Bakanlığı ve Temel Sağlık Hizmetleri Genel Müdürlüğü, 2011). Bunlarla birlikte, kanser hastalarına yönelik sosyal ve sağlık politikaları onların psikolojik, fiziksel ve sosyal ihtiyaçlarını büyük bir oranda ihmal etmektedir. Öte yandan bakım sağlayan aile üyelerinin psikolojik ve sosyal ihtiyaçları yok sayılmaktadır. Son olarak, formel sektörde kanser hastalarına yönelik koruyucu iş kanunları bulunsa da (SGK, 2013), enformel sektörde çalışan kanser hastalarına ve bakım sağlayanlarına yönelik herhangi bir koruyucu düzenleme bulunmamaktadır.

Ülkelerin kanser hastaları ve bakım sağlayan aile üyelerine yönelik sağlık ve sosyal politika pratikleri analizi tamamlandıktan sonra Türkiye'deki meme kanserli kadınların ve bakım sağlayan aile üyelerinin deneyim, ihtiyaç ve sorunlarını anlamak amacıyla yarı yapılandırılmış derinlemesine mülakatlar gerçekleştirilmiştir. Bu görüşmeler hem Orta Doğu Teknik Üniversitesi İnsan Araştırmaları Etik Kurulu'nun hem de hastane yönetimlerinin izni ve onayı doğrultusunda gerçekleştirilmiştir. Bu tez için Ankara ve İzmir'de 16 meme kanserli kadın, 7 bakım sağlayan ve 4 onkoloji uzmanı ile görüşülmüştür. İzmir'de Tepecik Eğitim ve Araştırma Hastanesi'nde, Ankara'da Hacettepe Eğitim ve Araştırma Hastanesi'nde görüşmecilere ulaşılmıştır. Bu hastaneler bölgelerinin en büyük ve gelişmiş hastaneleri arasındadır ve ikisi de çevre illerden hasta kabul etmektedir. Görüşmecilerin bir kısmına Bir Yaşayan Bir Bilen isimli meme kanserli kadınlar yardımlaşma ve destek grubu aracılığıyla ulaşılmıştır.

Tüm görüşmelerde katılımcıların kişisel bilgileri saklı tutulmuş ve katılım onayı alınmıştır. Görüşmeler yarım saat ile iki saat arasında değişmiştir. Katılımcıların istemedikleri sorulara yanıt vermemeleri ve görüşmeyi istedikleri anda sonlandırma hakları saklı tutulmuştur. Analiz esnasında her bir katılımcı farklı bir renk koduyla isimlendirilmiş ve kişisel bilgileri tez metninde paylaşılmamıştır. Saha çalışması meme kanserinin hastalar ve bakım sağlayan aile üyeleri üzerindeki fiziksel, psikolojik, ekonomik ve ailesel etkilerini ortaya çıkartmıştır. Bunlarla birlikte meme kanserli kadınların ve bakım sağlayan aile üyelerinin yaşam ve bakım kalitelerini olumsuz yönde etkileyen birçok kurumsal eksiklikler tespit edilmiştir. Saha çalışmasından elde edilen bulgular beş temel başlık altında analiz edilmiştir.

Meme kanseri ve tedavisi hastalar üzerinde çok derin fiziksel etkiler yaratmaktadır. Bu etkiler halsizlik, ağrı, uykusuzluk, kolda ödem toplanması, mide bulantısı, tat ve koku değişimi ve hassasiyeti, kilo değişimi, saç dökülmesi, deride renk ve şekil değişiklikleri ve memenin alınması olarak özetlenebilir (Byar, Berger, Bakken & Cetak, 2006; Beck, Dudley & Barsevick, 2005; McGarvey, Baum, Pinkerton & Rogers, 2001; Paskett & Stark, 2000). Tüm bu etkiler, hastaların günlük hayatlarında direk olumsuz yönde etki yaratmaktadır. Katılımcıların neredeyse tamamı özellikle ev işlerinde, yemek ve temizlik aktivitelerinde eskiden yapabildikleri birçok şeyi artık gerçekleştiremez olduklarını belirtmişlerdir. Bu sebeple, meme kanserli kadınların fiziksel yardıma ihtiyaçları bu süreçte çok artmaktadır. Aynı şekilde, tedaviye bağlı olarak yaşadıkları beden algılarındaki değişiklikler de hastalar üzerinde olumsuz etkiler yaratmaktadır. Radyoterapiye bağlı ciltteki renk ve doku değişiklikleri ve kemoterapiye bağlı saç dökülmesi günlük hayatlarını olumsuz etkilemektedir.

Meme kanserinin ve tedavi sürecinin fiziksel etkileri bakım sağlayan aile üyelerin üzerinde de derin etkiler yaratmaktadır. Meme kanserli kadınların fiziksel ihtiyaçlarının temel sağlayıcıları konumunda olan aile üyeleri yaşam rutinlerini yeniden düzenlemek zorunda kalmaktadırlar çünkü bu ihtiyaçlar en çok zaman gerektiren sorumluluklardandır. Ev temizliği, yemek yapımı, ulaşım ve kişisel bakım çok yoğun fiziksel emek gerektirmektedir ve bakım sağlayan aile üyeleri bu ihtiyaçların üstesinden kendi imkânlarıyla gelmeye çalışmaktadırlar. Ekonomik olarak karşılayabilecek gücü bulunan aileler ev işleri ve yemek için düzenli bir yardımcı tutmaktadırlar. Ancak bu ekonomik güce sahip olmayan aileler büyük fedakârlıklar yaparak bu ihtiyaçları karşılamaya çalışmaktadırlar.

Meme kanseri ve tedavisinin hastalar üzerinde yarattığı diğer bir sonuç psikolojik etkidir. Psikolojik etkiler, depresyon, kaygı bozuklukları ve geleceğe yönelik korku olarak özetlenebilir (Simard, et al., 2013). Bu sorunları genellikle aile üyeleri ve arkadaş gibi kendi birincil destek kanalları yardımlarıyla çözmeye çalışmaktadırlar. Sadece birkaç katılımcı düzenli olarak profesyonel psikolojik destek aldığını belirtmiştir. Bunun temel sebebi hastanelerde sigorta kapsamında sürekli bir psiko-onkolojik desteğin sunulmamasıdır. Profesyonel terapinin yanı sıra sosyal destek gruplarının da bu sürecin atlatılmasında faydalı olduğu görülmüştür. Bir Yaşayan Bir Bilen gibi meme kanserli kadınların ortak deneyim, duygu ve düşüncelerini paylaşabilecekleri sosyal destek grupları sayesinde kendilerini yalnız hissetmeyen ve süreç ile ilgili gerekli bilgiye direk ulaşabilen meme kanserli kadınların, bu dönemi daha kolay atlattıkları görülmüştür. Ancak bazı katılımcıların bu süreçle ilgili duygu ve düşünceleri hakkında konuşmak istemedikleri ve hastalıklarını bir sır gibi saklamayı tercih ettikleri de görülmüştür. Bu saklama davranışının temel sebebi hastalıklarını paylaştıklarında çevrelerinden beklentiye girmekten ve aile ve arkadaşlarının bu beklentileri karşılamayıp onları hayal kırıklığına uğratacağından korkmalarıdır. Bu durumdaki meme kanserli kadınların sürece ilişkin kaygı ve korkularını kendi içlerinde çözmeye çalıştıklarını söylemek mümkündür.

Her nasıl atlatmaya çalışırlarsa çalışsınlar, hastaların tamamı için meme kanseri hayatlarını temelinden değiştiren bir deneyimdir. Meme kanserli kadınlar kanserin Tanrı veya hayat tarafından kendilerine gönderilmiş bir sınav veya işaret olduğuna inanma eğilimi göstermektedir. Meme kanserli kadınların birçoğu tedavi süreçlerindeki deneyimleriyle dini ve manevi değerleri birleştirmeye çalıştırmaktadırlar. Bu şekilde bu dönemde yaşadıkları zorluklara kutsal anlamlar yükleyerek ihtiyaç duydukları gücü ve dayanma kuvvetini kendileri oluşturmaktadırlar.

Kanser teşhisi ve tedavi süreci bakım sağlayan aile üyelerinde de derin psikolojik etkiler yaratır. Daha önce de belirtildiği gibi tedavi sürecinde aile üyelerinin hayatlarında büyük değişiklikler meydana gelmektedir. Bunun temel sebebi, meme kanserli kadınların artan ihtiyaçlarını karşılamaya çalışan aile üyelerinin tüm yaşam rutinlerini yeniden düzenlemek zorunda kalmalarıdır. Aynı zamanda tedavi sürecinin sorunsuz ilerlemesi için bakım sağlayanların büyük sorumluluklar üstlenmesi gerekmektedir. Hayatlarındaki bu değişiklik psikolojik sorunlara yol açabilmektedir. Bu sorunların bir diğer sebebi de hastalığın seyri ve sonuçları ile ilgili yaşadıkları korku ve kaygılardır. Sevdikleri birisinin bu hastalıkla baş etmeye çalışması aile üyelerinin psikolojisini olumsuz etkilemektedir.

Meme kanserinin bir diğer çarpıcı etkisi de ekonomiktir. Ekonomik etkiler ilaç ve ek destekler gibi medikal olabileceği gibi, ulaşım, yardımcı maaşı ya da gelirde düşüş gibi medikal olmayan dolaylı etkiler de olabilir. Medikal harcamaların en büyük kısmı kanser tedavisinin kişiselleştirilmesi aşamasında karşımıza çıkmaktadır. Her bir kanser hastası için en etkili ve faydalı tedavi tümör tipine, aşamasına, hastanın yaşına ve diğer kişisel özelliklerine göre değişiklik göstermektedir. Özellikle ileri seviyedeki kanser hastaları daha etkili ve güçlü ilaçlara ihtiyaç duyarmaktadır ve bu ilaçlar daha pahalıdır. Türkiye'de kişiselleştirilmiş kanser tedavisi uygulaması olmadığı için bazı kanser hastaları, hastalıklarının özelliklerine göre doktor değişimi, farklı tedavi yöntemleri veya ek besin takviyelerine ihtiyaç duyabilmektedir. Bu ek ilaçların temini hastalar ve aileleri üzerinde ek bir harcama kalemi oluşturmaktadır.

Ulaşım medikal olmayan, dolaylı ama önemli bir harcama alanıdır. İki tip ulaşım masrafından bahsedebiliriz. Birincisi, hastanın yaşadığı şehirde tedavi için yapılan ulaşım harcamalardır. İkincisi ise, gerekli tedaviye ulaşmak için şehir değiştirildiğinde yapılan ulaşım harcamalardır. Şehir içi ulaşımda hastalar hastaneye giderken toplu taşıma kullanmaktan kaçındıklarını belirtmişlerdir. Bunun temelde iki sebebi vardır. İlki zayıflayan bağışıklık sistemleri sebebiyle toplu taşıma araçlarında hastalık kapacaklarından korkmalarıdır. Diğer sebep ise, tedavi sürecinin yan etkisi olan halsizlik ve ağrının, toplu taşıma araçları kullanmalarını neredeyse imkânsız hale getirmesidir. Bu durumda şahsi arabası olan hastalar dışında kalan meme kanserli kadınların aile üyeleri veya arkadaşlarının yardımıyla hastaneye ulaşmaya çalıştıkları görülmüştür. Bu durum ek bir maddi yük oluşturmaktadır. Bu tür bir imkânı bulunmayan ve zorunlu olarak toplu taşıma ile tedavi görecekleri hastanelere ulaşan kadınların yaşam kalitelerinde önemli bir düşüş görülmektedir.

Öte yandan altyapı ve insan kaynakları eksikliği sebebiyle tedavi için şehir değiştirmek zorunda kalan meme kanserli kadın ve aile üyeleri yeni bir harcama ile yüz yüze gelmektedirler. Bu durumda kalan hastaların ulaşım masraflarının kısmi olarak karşılanmasını düzenleyen bir yönetmelik bulunmaktadır. Ancak hem ödemeye hak kazanmak için uzun bir süreç olan sevk zincirinin tamamlanması gerekmektedir hem de hastanın bu ödeme için uygunluğunu kanıtlaması beklenmektedir. Zaten tedavinin etkileriyle başa çıkmaya çalışan hastalar, bu masrafın bir kısmını geri almak için başvurmak konusunda çekimser davranmaktadır. Aynı şekilde şehir değiştirildiğinde konaklama ve yeni bir şehirde yaşamak gibi ek masraflarla da başa çıkmaya çalışmaktadırlar. Bazı belediyeler kanser hastalarına yönelik konaklama hizmetleri sunmaktadır ancak katılımcılarının çoğunun bu hizmetten haberdar olmadığı görülmüştür.

Harcamaların artması kadar ailedeki gelirin azalması da kanserin ekonomik etkilerinden birisidir. Çoğu durumda meme kanserli kadın tedavi sürecinde çalışmaya devam etmemektedir. Bazı katılımcılar, hem maddi sıkıntılar hem de enformel sektörün düzensiz yapısından ötürü işlerini tamamen kaybetme korkusuyla çalışmaya devam ettiklerini ancak bunun kendileri için çok zor olduğunu belirtmişlerdir. Tedavi sürecine devam ederken tam zamanlı olarak çalışmak zorunda kalan meme kanserli kadınların zaman zaman tedavilerinde aksama yaşadıkları görülmüştür. Hastaların yanı sıra bakım sağlayan aile üyelerinin çalışma yaşamları da tedavi sürecinden olumsuz etkilenmektedir. Bakım sağlayan aile üyeleri bir işte çalışırken aynı zamanda bir diğer tam zamanlı iş olarak görülebilecek bakım sağlama sorumluluklarını yerine getirmeye çalışmaktadırlar. Artan sorumlulukları çalışma yaşamlarında eksik günler, verimlilik düşmesi ve işe ara verme gibi sorunlara yol açmaktadır.

Meme kanserli kadınlar ve bakım sağlayan aile yakınlarıyla yapılan derinlemesine mülakatlarda ortaya çıkan bir diğer etki alanı aile içi ilişkilerdir. Kanser ve tedavi süreci tüm aile üyelerinin yaşamlarını yeniden düzenlemelerine ve bakım zincirinde bir rol üstlenmelerine neden olmaktadır. Değişim yaşanan ilişkilerden ilki eşler arasındakidir. Bu süreçte çiftler arasındaki ilişki yeni anlamlar kazanmaktadır. Bu yeni anlamlar çoğunlukla aile üyelerinin inanç sistemleri ve dünya görüşleriyle şekillenmektedir. Katılımcıların neredeyse tamamı bu süreci eşler arası ilişkide bir test veya sınav olarak görmektedir. Bu zorlu süreçte birbirine destek olan çiftlerin ilişkileri güçlenirken, tedavi sürecini eşleri tarafından bekledikleri desteği almadan sürdüren hastaların eşleriyle ilişkileri kalıcı hasarlar almaktadır. Meme kanserli kadınlar eşlerinin kendilerine sağladıkları destek ile ilişkilerini yeniden şekillendirmektedirler.

Bu dönemde değişim yaşayan bir diğer ilişki anne-çocuk ilişkisidir. Kanser tedavi süreci annenin sabit ve sürekli olan bakım sağlayan ebeveyn rolünü sarstığından çocuklarıyla yeni bir ilişki biçimi ortaya çıkabilmektedir. Çocuklarının yaşı daha büyük olan anneler bu süreci daha kolay atlatabilmektedir çünkü yaşı daha büyük olan çocuklar annelerinin bakımına daha az gereksinim duyduklarından tedavi sürecinde annelerine bakım sağlamak onlar üzerinde çok büyük ve sarsıcı bir etki yaratmayabilmektedir. Ancak yaşı daha küçük olan çocuklu kadınların tedavi sürecinin etkilerini çok daha derinden hissettikleri görülmektedir. Artık bakıma ihtiyaç duyan ve kanser sebebiyle derin fiziksel ve psikolojik etkiler yaşayan kadınlar annelik rollerini eskisi gibi sürdüremeyebilir. Bu hem çocukları üzerinde hem de kendi annelik rollerine bakışı açısından sarsıcı izler bırakmaktadır. Bunlarla birlikte kanser tedavisi kadınların doğurganlıklarını olumsuz etkileyebildiğinden çocuğu olmayan ya da bir çocuk daha yapmak isteyen kadınların annelik planlarında kalıcı değişiklikler yaratmaktadır. Aynı şekilde tedavinin sonucundan emin olamayan ya da kanserin tekrarlamasından korkan kadınlar çocuk sahibi olma planlarında kendi seçimleri dışında değişiklikler yapmak zorunda kalabilmektedir.

Kanserin aile içi ilişkilerdeki bir diğer etkisi bakım sağlayan aile üyelerinde görülmektedir. Aile üyeleri bakım işlerinin bölüşümü üzerine kendi aralarında pazarlık yapmak eğilimi gösterebilmektedir. Bu pazarlıklar yaş, iş hayatı, sosyoekonomik durum, yaşam yeri ve aile üyesinin istekliliği gibi farklı kriterlere bağlı olarak yapılmaktadır. Aynı şekilde aile üyelerinin cinsiyeti de bakım işlerinin bölüşümünün ayarlanmasında çok önemli bir faktördür. Kadın aile üyeleri fiziksel ve duygusal destekten sorumlu iken, erkek üyeler ulaşım, bilgiye ulaşma ve ekonomik destek alanlarında sorumluluk üstlenmektedirler. İşbölümü pazarlık süreci aile üyeleri üzerinde kısa veya uzun süreli gerilimlere sebep olabildiği gibi aile içi ilişkileri sağlamlaştırabilmektedir.

Görüşmelerde ortaya çıkan bir diğer eksiklik ise kurumsal yetersizliklerdir. İlk olarak meme kanserli kadınların çoğu kanseri tesadüfen ve geç aşamalarda keşfettiklerini belirttiler. Bu sebeple mevcut tarama hizmetlerinin yeterli olmadığını söylemek mümkündür. Aynı zamanda birçok hasta ve hasta yakını hastalık, tedavi süreci, farklı tedavi seçenekleri, yan etkiler ve hastane/doktor önerileri ile alakalı bilgiye ulaşmada sorunlarla karşılaştıklarını paylaştılar. Diğer bir kurumsal eksiklik onkoloji çalışanlarının hasta ve bakım sağlayan aile üyeleriyle iletişimlerinde görülmüştür. Hasta ve hasta yakınları sağlık personellerinin davranışlarından birebir etkilenmektedirler. Hastaya kanser teşhisinin ilk açıklanışının meme kanserli kadın üzerinde yarattığı etki çok çarpıcıdır. Benzer şekilde tedavi sürecinde doktorların, hemşirelerin ve radyologların hastalara olumsuz davranışları hastanın tedavi sürecini ters yönde etkilemekte, hatta bazı durumlarda hastanın tedaviyi yarım bırakmayı düşünmesine dahi yol açmaktadır.

Türkiye'deki kanser tedavi merkezleri servis, altyapı ve ekipman bakımında büyük eksiklikler barındırmaktadır. Bu eksiklikler tedavi sürecini aksatabildiği gibi hastaların bakım ve yaşam kalitelerini derinden etkileyebilmektedir. Meme kanserli kadınlar kanser tedavisi bittikten sonra da fiziksel, ekonomik ve psikolojik etkileri deneyimlemeye devam etmektedir. Bunun en yaygın örneği hastalığın tekrarlayacağı korkusudur. Tekrar aynı süreci yaşamaktan korkan hastalar günlük hayatlarında kısıtlamaya gidebilmektedir. Ancak hastaneye gidiş gelişleri bittiği için çevrelerinde kaygı ve korkularını paylaşabilecekleri kimsenin kalmadığını belirtmektedirler.

Son olarak, aşağıda, farklı ülkelerin kanserle alakalı sosyal ve sağlık politikaları taramasından, Türkiye'nin kanser hastalarına yönelik sunduğu politikalarının analizinden ve meme kanserli kadınlar, bakım sağlayan aile üyeleri ve uzmanlarla yapılan yarı yapılandırılmış derinlemesine mülakatlardan elde edilen bulgular ışığında kanıta dayalı sağlık ve sosyal politika önerilerinde bulunulacaktır.

Dünyada kişiselleştirilmiş kanser tedavisi son yıllarda artan bir hızla tartışılmaya başlanmıştır. Kişiselleştirilmiş tedavide, hastanın yaşını, cinsiyetini, genetik özelliklerini, tümörün tipini, boyutunu ve aşamasını dikkate alan, kişiye özel en uygun tedavinin sunulması amaçlanır. Bu şekilde yan etkiler minimize edilir ve tedavinin etkisi arttırılır. Ancak Türkiye'de tüm hastalara tek tip bir tedavi sunulmakta, ileri aşama meme kanserli kadınlar kullanmaları gereken ek takviye ilaç ve besin kaynaklarını bütçeleri elverdiğince edinmeye çalışmaktadırlar. Bu sebeple, sağlık sistemi kişiselleştirilmiş kanser tedavisi sunabilecek çok-disiplinli tedavi ekipleri oluşturmalıdır.

Meme kanseri ve tedavi süreci hastalar üzerinde derin fiziksel etkiler yaratır. Bu etkiler sebebiyle meme kanserli kadınlar günlük hayatlarını ve kişisel bakımlarını sürdürmekte sürekli yardım ve desteğe gereksinim duymaktadır. Bu ihtiyaçlar genellikle aile üyeleri tarafından karşılanmaya çalışılsa da hem bakımın kalitesi hem de sürekliliği açısından önemli sorunlara yol açabilmektedir. Özellikle aile üyelerinden destek görmeyen kadınların bu süreci çok ağır ve zor atlattıkları görülmüştür. Bu nedenlerle ev işleri ve yemek için düzenli destek sunulmalıdır.

Tedaviye ulaşmak hastalar için büyük bir sorun teşkil etmektedir. Hem şehir içi hem de şehirlerarası ulaşım meme kanserli kadınlarda ve bakım sağlayan aile üyelerinde fiziksel, ekonomik ve psikolojik sorunlara yol açmaktadır. Kanser tedavilerine ulaşımlarını kolaylaştırmak ve düzenli hale getirmek için ulusal bir taşıma servisi sunulmalıdır.

Meme kanserli kadınlar ve bakım sağlayan aile üyeleri, tedavi sürecinde çalışma yaşamlarında zorluklar deneyimlemektedirler. Özellikle enformel sektör çalışanları işlerinin güvencesiz olmasından ötürü çalışmaya devam etmek zorunda hissetmekte, tedavi sürecinin tüm zorluklarına rağmen çalışma yaşamlarına devam etmeye çalışmaktadırlar. Aynı şekilde bakım sağlayan aile üyeleri de çalışma yaşamlarında olumsuzluklarla karşılaşabilmektedir. Bu sorunlar, kanser hastaları ve bakım sağlayanların çalışma hayatlarına yönelik yasal düzenlemeler yapılmasını gerekli kılmaktadır.

Mevcut sağlık sisteminde hasta ve yakınlarına yönelik psiko-onkolojik desteğin çok yetersiz olduğu bir gerçektir. Sadece ekonomik olarak karşılayabilecek güce sahip hasta ve yakınları psikolojik destek alırken, diğerleri deneyimledikleri zorlukları kendi başlarına atlatmaya çalışmaktadırlar. Hastanelerde sürekli hizmet sunan psiko-onkolog sayısındaki yetersizlik hastaların ve bakım sağlayanların yaşam kalitelerini olumsuz yönde etkilemektedir. Her kanser tedavi ünitesi hasta ve yakınlarına düzenli hizmet sunacak psiko-onkolog istihdam etmelidir. Benzer şekilde aileler de kanser ve tedavi sürecinden çok derinden etkilenmektedir. Bu etkiler kalıcı ve olumsuz olabilmektedir. Bu nedenle sunulacak düzenli aile terapileri kanser tedavisinin ve artan bakım sorumluluklarının yarattığı olumsuz etkinin daha kolay atlatılmasına yardımcı olabilir. Aileler bu süreçte birincil bakım kaynağı olarak kabul edilmektedir, ancak tek bir aile tipinin olduğu ön kabulü gerçekte işlememektedir. Yalnız yaşayan kadınlar veya aile içi ilişkilerinin farklı kurgulandığı ailelerde kanser tedavi sürecinin hasta açısından çok daha zor atlatıldığı görülmüştür. Bu durum göz önünde bulundurularak sağlık ve sosyal politikaların ve pratiklerin aileler arası farklılıklar göz önünde bulundurularak düzenlenmesi gerekir.

Kanser tedavisi oldukça uzun ve zorlu bir süreçtir. Teşhisin hastayla ilk paylaşıldığı andan tedavinin son gününe dek onkoloji profesyonellerinin davranışları hasta ve yakınlarının yaşam ve bakım kaliteleri üzerinde derin etki bırakmaktadır. Ancak mevcut sistemde onkoloji uzmanlarının iletişim ve davranışlarında temel sorunlar olduğu göze çarpmıştır. Bu eksikliğin giderilmesi için onkoloji uzmanlarının iletişim yeteneklerini geliştirmeye yönelik zorunlu eğitim programları düzenlenmelidir.

Hastane, şehir ve bölgeler arasında kanser tedavisinde altyapı, ekipman ve insan kaynakları bakımından büyük eşitsizlikler olduğu görülmüştür. Temel kanser tedavisine ulaşabilmek için bile şehir hatta bölge değiştirmek zorunda kalan hastalar süreçten fiziksel, ekonomik ve psikolojik olarak olumsuz etkilenmektedir. Bu eşitsizliklerin giderilmesi ve meme kanserli kadınların tedaviye sorunsuz ve kolaylıkla ulaşmalarının sağlanması gerekmektedir.

Bu süreçte hasta ve yakınlarının eksikliğini en çok hissettiklerini belirttikleri alan bilgi ve bilgiye ulaşmadır. Özellikle kanserin kendisi ve tedavi sürecine ilişkin herhangi bir bilgiye ulaşmanın oldukça zor olduğu görülmüştür. Bu sebeple Sağlık Bakanlığı tarafından kanser ve tedavi süreci hakkında yeni bilgilendirme kanallarının açılması gerekmektedir.

Meme kanserli kadınlar ve yakınları tedavi(ler) sürecinde hastane değiştirdiklerinde tedavilerinde aksaklıklar yaşayabilmektedirler. Hastaneler arası bilgi alışverişi oldukça azdır. Bakanlık tarafından kanser tedavi sürecinin bütün aşamalarıyla ilgili gerekli bilgileri tutabileceği ulusal bir veri tabanı oluşturulmalıdır. Bu sayede hastalar hastane değiştirdiklerinde bir önceki tedavilerine eksiksiz devam edilebilecektir. Aynı zamanda bu uygulama sayesinde hem hastaya doktor ve hastane seçme hakkı tanınacaktır, hem de kişiselleştirilmiş kanser tedavisi çalışmaları için önemli bir karşılaştırma deposu oluşturacaktır.

Ülkelerin kanser ile mücadelede izledikleri tüm aşamaları, özellikle sosyal politikaları bağlamında karşılaştırmalı sunabilecek bir veri tabanı eksiktir. Kanser ile alakalı sosyal politika deneyimlerinin paylaşıldığı uluslararası bir veri tabanı oluşturulmalıdır. Bu sayede ülkelerin daha iyiye ulaşmak için birbirleriyle bilgi alışverişinde bulunabilecekleri bir altyapı kurulmuş olacaktır.

Bu tezin en önemli bulgularından birisi de güncel sağlık sisteminde meme kanseri tedavisi sürecinde sosyal hizmet uzmanlarının rolünün çok kısıtlı olmasıdır. Sosyal hizmet uzmanlarının bu süreçte daha aktif rol almaları adına düzenlenecek çok-disiplinli takımlara dâhil edilmeleri hasta ve yakınlarının tedavi sürecinin zorluklarını daha kolay atlatmalarını sağlayacaktır. Bu şekilde meme kanserinin psiko-sosyal boyutu da tedavi sürecine dâhil edilmiş olacaktır.

Meme kanseri ve tedavisinin sarsıcı etkileri, tedavinin bitmesiyle sonlanmaz. Bu sürecin hem fiziksel hem de psikolojik etkileri hastanın önceliklerini, hayat rutinini ve karakterini şekillendirmeye devam etmektedir. Üstelik artık hastaneye gidiş gelişleri azalmış olan hastalar tüm soru ve kaygılarını kendi içlerinde çözmeye çalışmaktadır. Tedavi sonrası yaşamlarına alışmalarını kolaylaştırmak için düzenli takip ve terapi planları geliştirilmelidir.

APPENDIX D: TEZ FOTOKOPİSİ İZİN FORMU

ENSTİTÜ

Fen Bilimleri Enstitüsü ☐

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Uygulamalı Matematik Enstitüsü ☐

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Deniz Bilimleri Enstitüsü ☐

YAZARIN

Soyadı : Erçin
Adı : Hazal
Bölümü : Sosyal Politikalar Ana Bilim Dalı

TEZİN ADI (İngilizce) :

LIVING WITH BREAST CANCER: POLICY PRACTICES AND RECOMMENDATIONS

TEZİN TÜRÜ : Yüksek Lisans ■ Doktora ☐

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