

BREAST CANCER PATIENT PATHWAYS TO TREATMENT
IN TURKEY’S INTERNAL HEALTHCARE MARKET:
A QUALITATIVE STUDY

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A QUALITATIVE STUDY

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DECLARATION OF ORIGINALITY

I, Zeynep Kesici, certify that

- I am the sole author of this thesis and I have fully acknowledged and documented in my thesis all sources of ideas and words, including digital resources, which have been produced or published by another person or institution;
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ABSTRACT

Breast Cancer Patient Pathways to Treatment in Turkey's Internal Healthcare Market: A Qualitative Study

The importance of managing noncommunicable diseases, such as cancer, has been viewed as a vital component of Universal Health Coverage (UHC) due to their worldwide high prevalence, significant disease burden, and sometimes life-long medical ramifications for patients. Having been deemed an achiever of UHC, Turkey has implemented an internal market for healthcare to achieve equal access to healthcare. Against this background, this thesis explores breast cancer patients' experiences of access and pathways to treatment in private hospitals offering publicly-funded services (PHOPS) in Turkey. It examines the factors that shape these pathways and the implications of these pathways for patients. This thesis relies on a thematic analysis of an exploratory qualitative study that includes 12 semi-structured in-depth interviews conducted between July and August 2021 with female breast cancer patients using private hospitals. It reveals two interrelated factors that shape patient pathways during the diagnosis and treatment stages: the projected cost of treatment and barriers to accessing integrated medical care. Based on these two factors, two distinct patient pathways, insured and underinsured patient pathways, are identified. While patients with private health insurance alongside compulsory general health insurance experience easy access to timely and effective treatment (insured pathway), those who only count on the latter deal with complicated processes of accessing treatment such as combining different providers (underinsured pathway). The thesis concludes that the insurance status of patients has a significant influence on experiences of access and pathways to treatment in PHOPS.

ÖZET

Türkiye Sağlık Hizmetleri İç Pazarında

Meme Kanseri Hastalarının Tedaviye Erişim Patikaları: Nitel Bir Araştırma

Kanser gibi bulaşıcı olmayan hastalıkların yönetilmesinin önemi, bu hastalıkların yüksek prevalansları, oluşturdıkları ciddi hastalık yükü ve bazı hastaları etkileyen yaşam boyu tıbbi sonuçları nedeniyle Evrensel Sağlık Güvencesi (ESG)’nin hayati bir bileşeni olarak görülmektedir. ESG sağlayan ülkeler arasında kabul edilen Türkiye, hizmete erişimde eşitlik sağlamak amacıyla hizmet sunumunda iç piyasa modeli uygulamaktadır. Bu tez Türkiye’de meme kanseri hastalarının kamu tarafından finanse edilen hizmetler sunan özel hastanelerdeki tedaviye erişim deneyimlerini ve tedavi patikalarını araştırmakta, bu patikaları şekillendiren faktörleri ve bu patikaların hastalar açısından sonuçlarını incelemektedir. Tez kapsamında özel hastanelerden hizmet alan 12 meme kanseri hastası kadınla 2021 yılının Temmuz ve Ağustos aylarında yarı yapılandırılmış derinlemesine görüşmeler gerçekleştirilmiş ve bu veriler keşfedici nitel tematik analiz yöntemiyle değerlendirilmiştir. Tez öngörülen tedavi maliyeti ve entegre kanser tedavisine erişimin önündeki engellerin tedavi patikalarını şekillendiren iki faktör olduğunu iddia etmektedir. Bu iki faktör iki farklı hasta patikası ortaya çıkarmaktadır: sigortalı ve eksik sigortalı. Özel sağlık sigortalılar (sigortalı patika), zamanında ve etkili tedaviye kolay erişim sağlayabilmekteyken, zorunlu genel sağlık sigortalılar (eksik sigortalı patika), farklı hizmet sunucuları bir arada kullanmak durumunda kalmak gibi tedaviye erişimde karmaşık süreçlerle uğraştıklarını vurgulamaktadırlar. Bu tez, hastaların sigorta durumunun, anlaşmalı özel hastanelerde tedaviye erişim ve tedavi patikaları üzerinde önemli bir etkiye sahip olduğu sonucuna varmaktadır.

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*Dedicated to the memory of my beloved grandmother,
Neyyire Perran Dođancı*

TABLE OF CONTENTS

CHAPTER 1 INTRODUCTION	1
1.1 Research design and methodology.....	6
1.2 Data collection and participants	7
1.3 Data analysis	12
1.4 Outline of the chapters	13
CHAPTER 2 A CRITICAL REVIEW OF THE LITERATURE ON HEALTHCARE SYSTEMS AND PATIENT PATHWAYS IN BREAST CANCER TREATMENT	14
2.1 An introduction to healthcare systems in the past and present	15
2.2 The blurring public-private boundaries in healthcare systems	20
2.3. Patient experiences in accessing treatment in hybrid healthcare systems	32
2. 4 Conclusion	40
CHAPTER 3 BREAST CANCER IN THE TURKISH CONTEXT	43
3.1 Turkish Healthcare System	45
3.2 Breast cancer in the Turkish healthcare system	53
3.3 Existing studies on Turkish breast cancer patients	60
3.4 Conclusion	70
CHAPTER 4 A QUALITATIVE ANALYSIS OF BREAST CANCER PATIENT PATHWAYS TO DIAGNOSIS AND TREATMENT IN TURKEY	72
4.1 Introduction	72
4.2 Breast cancer patients' treatment pathways	75

4.3 Factors affecting the bifurcation of treatment pathways.....	86
4.4 Conclusion	98
CHAPTER 5 CONCLUSION.....	104
APPENDIX A SEMI-STRUCTURED INTERVIEW QUESTIONS	111
APPENDIX B SEMI-STRUCTURED INTERVIEW QUESTIONS (TURKISH).....	113
APPENDIX C CONSENT FORM	115
APPENDIX D CONSENT FORM (TURKISH)	118
APPENDIX E ETHICS COMMITTEE APPROVAL FORM	121
APPENDIX F QUOTATIONS IN TURKISH	122
REFERENCES.....	130

ABBREVIATIONS

BCS	Breast-conserving surgery
GSS	General Health Insurance (<i>Genel Sağlık Sigortası</i>)
HTP	Health Transformation Program
KETEMs	Kanser Erken Teşhis, Tarama ve Eğitim Merkezleri
MoH	Ministry of Health
MRI	Magnetic resonance imaging
NCDs	Noncommunicable diseases
NHS	National Health Services
NPM	New Public Management
OECD	Organization for Economic Development and Cooperation
PET	Positron emission tomography
PHI	Private Health Insurance
PHOPS	Private-hospitals-offering-publicly-funded-services
PPS	Purchaser-provider split
QoL	Quality of life
SDGs	Sustainable Development Goals
SGK	Social Security Institution (<i>Sosyal Güvenlik Kurumu</i>)
SUT	Sağlık Uygulama Tebliği
UHC	Universal health coverage
UN	United Nations
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

Due to sudden illnesses, people exhaust their entire life savings, if they have any, or go into debt due to excessive healthcare costs, which thrusts millions into extreme poverty across the world every year, thus enshrining a vicious poverty trap from which it becomes more difficult to escape. This is especially striking in countries that are deemed to achieve universal health coverage (UHC).

The emphasis on non-communicable diseases (NCDs) on the global health agenda has become greater than ever (Gyasi & Phillips, 2020). Many NCDs, including cancers, diabetes, cardiovascular and respiratory diseases have been identified by the World Health Organization (WHO) as the leading causes of poor health and mortality worldwide (World Health Organization [WHO], 2021). Particularly significant are problems of accessing treatment faced by vulnerable groups in society who tend to postpone or completely forgo healthcare due to drastically rising healthcare costs coupled with limited awareness and availability of adequate care regarding NCDs (McCracken & Phillips, 2017).

Along with the rise of NCDs to the top of the global health agenda has been the proliferation of a campaign towards achieving UHC, a key component of sustainable development through which all countries can achieve improved health outcomes. Over the recent decades, many international actors have stepped up efforts for UHC, fortified by the incorporation of UHC as one of the Sustainable Development Goals (SDGs) set by the United Nations (UN). Consequently, many countries have started to prioritize UHC on national policy agendas by instituting comprehensive programs that aim to implement UHC. On the other hand, the

implementation guidance and supervision concerning UHC have remained equivocal from a human rights standpoint (Nygren-Kraug, 2019).

Healthcare systems are ought to maintain a balance between the following trade-offs: equity in access, quality standard of healthcare, cost-containment, and range of available services (Anderson et al., 2006). The idea of UHC brings together the provision of essential services and adequate financial protection (Garrett et al., 2009; Rodin and de Ferranti, 2012; Carrin et al. 2013). However, the constituents that form “adequate coverage” is contested in the UHC literature (Stuckler et al., 2010) and, similarly, the notion of “access” has been defined in several different ways, meaning that these concepts should be outlined in relation to the context in which they are used (Thieren, 2005). This thesis will stick to the definition of UHC as a system in which “all people have access to the health services they need, when and where they need them, without financial hardship” (WHO, 2020).

Increasing emphasis upon UHC is facilitating access to both therapeutic and preventive healthcare services for NCDs (McCracken & Phillips, 2017). While UHC is extremely important for successfully addressing NCDs, targeting UHC with a tunnel vision might end up overemphasizing the expansion of access to healthcare services rather than ameliorating health outcomes in terms of NCDs (Schmidt et al., 2015). Without underestimating the key role of preventive approaches to NCDs as part of the UHC initiatives, this thesis focuses on the curative dimension only. It revolves around the relationship between NCDs and UHC both in terms of the challenges that the NCDs pose in the realization of UHC as well as the contribution of UHC in building a response to NCDs.

Healthcare systems across the world have undergone radical transformations and their organizational structures have increasingly become complex. They play a

role in this relationship in that they constitute the operational pillar, which enables one to make sense of all these macro-level policy discussions at the micro-level implementation. The variety in healthcare system typologies renders the literature on this field to be fruitful (Bambra, 2005; Burau and Blank, 2006; Böhm et al., 2013; Moran, 2000; Reibling, 2019; Wendt et al., 2009; Wendt, 2009, 2014). Similar to most social systems, however, healthcare systems are open to change, which is manifested in the hybridization trend followed by many healthcare systems as opposed to purer types observed in the pre-1980s period (Dragoonis, 2009; Rothgang et al., 2005, 2010; Reibling et al., 2019).

The emergence of successive healthcare reforms is associated with structural economic changes brought about by globalization (Walt, 1994), increasing demand for healthcare due to aging populations, the emergence of more expensive medical technologies, the growing awareness of available treatments, and the right to access to them (Moran, 2000), and the expansion of UHC, which puts more pressure on healthcare systems by boosting the number of beneficiaries (McKee et al., 2013). These factors together have increased the burden on healthcare systems, which has pointed to the need for comprehensive reform agendas in both developed and developing countries.

In this vein, the theme of the World Cancer Leaders' Summit that took place with the participation of 80 countries in 2019 was cancer and UHC, particularly how countries can enable access to quality cancer treatment for patients across the world as part of the global goal of achieving UHC (Johnson et al., 2020). In this landmark meeting, current financing of cancer treatment was deemed insufficient worldwide, and public-private partnerships were praised in that they create additional resources for the healthcare sector, but it was also highlighted that governments will have to

enhance their regulatory frameworks to safeguard the availability and quality of services (Johnson et al., 2020).

The journey towards UHC is erratic and often manifested in matters related to the affordability of all-inclusive healthcare services in developing countries where governments start to acknowledge the fact that a well-functioning healthcare system is a must for accomplishing development goals (McKee et al., 2013). In this regard, the establishment of internal markets for the provision of healthcare in publicly financed healthcare systems has been promoted and viewed as a solution to achieve UHC. Turkey followed this route.

The hybrid healthcare system in Turkey where private hospitals offering publicly funded services (PHOPS) have increasingly become prominent actors (Yılmaz, 2020), which is the focal point of this thesis and which, constitutes a case for exploring the relationship between UHC and NCDs.

In Turkey, the establishment of a compulsory General Health Insurance (*Genel Sağlık Sigortası*, GSS) scheme after the 2003 reforms under the Health Transformation Program (HTP) united the formerly fragmented insurance schemes under one roof. This was followed by the establishment of a purchaser-provider split (PPS) in financing and the adoption of an internal market for provision. These developments have enabled Turkey to meet the criteria for UHC.

As part of these efforts, the Turkish minister of labor and social security announced in 2018 that all kinds of additional fees and payment differences related to cancer treatment, surgery, and medicine were removed, that is, the Social Security Institution (*Sosyal Güvenlik Kurumu*, SGK) would henceforth fully cover standard cancer treatment through GSS (Medimagazin, 2018). In other words, private hospitals which hold a contract/protocol with the SGK would no longer be able to

charge any additional or contributory fees from Turkish citizens unless they require specific treatment or medicine that is not fully covered. This change has already been demarcated since 2010 by the Health Implementation Communiqué (*Sağlık Uygulama Tebliği*, SUT) (Official Gazette of the Republic of Turkey, 2010). Therefore, the minister's belated statement to the press in 2018 has done nothing more than stating that the annual budget previously allocated for cancer treatment (240 million Turkish Lira) had been increased up to 750 million Turkish Lira (Medimagazin, 2018).

Against this background, this thesis explores how breast cancer patients access treatment in PHOPS in the context of an internal market for healthcare provision in Turkey – counted as a leading performer of UHC. It seeks to unveil how the health insurance status of patients affects their breast cancer diagnosis and treatment pathways and what are the implications of these pathways in terms of access to quality medical care. Lastly, it examines what breast cancer patient experiences of access indicate about the functioning of the internal market for healthcare provision in Turkey.

The existing literature on the Turkish context focuses on various aspects of the healthcare system before and after the 2003 reforms (Ağartan, 2012, 2015, 2019, 2020; Başol & Işık, 2015; Ergün & Ergün, 2010; Ökem & Çakar, 2015; Tatar et al., 2007; Üstündağ & Yoltar, 2007; Yılmaz, 2013, 2017, 2020, 2021). However, although the financing and provision dimensions of the Turkish healthcare system have thus far been studied extensively, how their transformation has shaped patient pathways in general, and cancer patient pathways to diagnosis and treatment, in particular, is underexplored in the Turkish case. Hence, this thesis contributes to the nascent research agenda on the realized publicness of healthcare (Yılmaz, 2020) by

raising a discussion on UHC in the context of NCDs and by bringing breast cancer patient experiences of accessing healthcare into the broader research on healthcare systems and patient pathways.

1.1 Research design and methodology

Yılmaz (2020) shows that problematic patient experiences in accessing treatment appear as more pronounced especially when patients resort to PHOPS due to an emergency or chronic, rare, and/or complicated illnesses in the Turkish case.

This recent study provided me with a useful framework for examining breast cancer patient experiences in Turkey's internal healthcare market.

The rationale behind focusing on breast cancer in this thesis was two-fold. The former was a pragmatic reason in that breast cancer is a vital, yet treatable non-communicable disease that is prevalent amongst Turkish women (Çakmak et al., 2019). In addition, as mentioned before, since breast cancer treatment in both public and private providers is fully covered by the general social health insurance in Turkey, this research allows me to examine if and to what extent the statutory right to access breast cancer treatment is practiced on the ground.

How women make sense of breast cancer diagnosis is highly influenced, if not shaped, by the cultural settings and contexts in which they live (Terzioğlu & Hammoudeh, 2017). Therefore, the latter reason was more intuitive in that as a female researcher, examining the treatment pathways of breast cancer patients was particularly meaningful because talking about breast cancer can still be considered a taboo amongst Turkish women. This stems from its connotation amongst the population that the diagnosis of breast cancer is a traumatic event that leads to the depreciation of femininity and sensuality in the long run. That is to say, I have found

that being a female researcher presented me with a comparative advantage due to the intricacy of exploring this issue.

A qualitative exploratory methodology was employed in the course of this thesis. It was chosen to grasp the situation among breast cancer patients from their narratives, besides capturing novel insights and thus cultivating a more profound understanding of a particular phenomenon. That is to say, my goal as a researcher was to access the experiences of breast cancer patients, which entails questioning them about things that might be highly personal to them, however, it nonetheless facilitated me to gather data on in-depth patient experiences that could not be captured through a quantitative study (Sutton & Austin, 2015). In addition, the overall prevalence of problematic breast cancer patient experiences that this thesis aims to unveil was unknown, therefore, relying on qualitative methods was an appropriate choice in this study.

1.2 Data collection and participants

Istanbul was chosen as the research site for this study because it is the most populated city in the country where most of the PHOPS are located and it is also the city with the highest rate of private health insurance ownership. The sampling universe for this study included female breast cancer patients (holding Turkish citizenship and residing in Istanbul) who had used services in private hospitals offering publicly funded cancer treatment in the last year or are currently under treatment.

It is out of the question for a group of patients to go to public hospitals in Turkey in spite of the compulsory GSS. This can be characterized not only as a result of past negative experiences of patients in accessing healthcare services in public

hospitals but also as a result of a deep-rooted distrust towards public hospitals in Turkey among some sectors of the society. Since the narratives to be presented in this thesis are mostly built on this perception, I specifically focused on researching this patient group.

Semi-structured in-depth interviews were held with 12 female breast cancer patients during July and August 2021. The median age of the participants was 45. While 4 of the participants were retired, the remaining 8 were employed and had a variety of occupations (See Table 1). Although the participants had diverse educational backgrounds, those with the lowest education levels were high school graduates.

The participants were asked questions (listed in Appendices A and B) regarding their experiences in accessing breast cancer treatment. The initial interview questions were formed to concentrate on the narratives of patients about their experiences of receiving treatment rather than their experiences with the illness itself although the two might at times overlap to an extent. The interviews were conducted in Turkish, and the direct quotations were translated by the researcher. The mean interview length was 1 hour. Three of the interviews were conducted face-to-face and the remaining 9 were held online via Zoom due to concerns related to the Covid-19 pandemic. The interviews were audio-recorded with the informed consent of the informants and transcribed verbatim. The consent form is listed in Appendices C and D. All recordings that contain personal data were anonymized during the transcription process. Ethical approval for this study (No: 2021/68) was granted by the Ethics Committee for Master and Ph.D. Theses in Social Sciences and Humanities at Boğaziçi University (Appendix E).

The main inclusion criterion for this study was the use of private hospitals for breast cancer diagnosis and treatment within one year before the interview date. Both purposeful and snowball sampling were employed to recruit the participants as these two sampling methods are largely used to locate hard-to-reach populations (Biernacki & Waldorf, 1981). In addition, Turkish breast cancer patients have progressively become more outspoken about their illness experiences, which led to the foundation of many patient organizations that assist breast cancer patients and their relatives and raise awareness in society (Terzioğlu, 2012).

I have contacted several Istanbul-based non-profit cancer and breast cancer patient organizations and asked if they could disseminate the information about the research to their members so that those who would be willing to participate in the research could contact me individually via e-mail or telephone call. The rationale behind this was the prospect that patients who engage in some form of advocacy and joint action are more prone to build knowledge and experience (Palinkas et al., 2015). In addition, purposeful sampling was useful in finding participants who were available and eager to contribute to the research, thus facilitating the creation of a rapport between the informants and the researcher (Bernard, 2002). 7 potential participants who contacted me were provided with a more detailed account of the content and the purpose of the research as well as the interview procedures.

Snowball sampling was employed when 5 of those patients agreed to participate in the research as they were asked if they could refer to other breast cancer patients they knew. The snowball sampling method was chosen alongside purposeful sampling because it grants the researcher the opportunity to create better communication with additional participants as they would be acquaintances of the first participants who would already be linked to the researcher (Ghaljaie et al.,

2017). Considering that the subject matter of the interview is an intricate topic, this sampling method was deemed suitable for providing a leeway for the researcher to build rapport with the interviewees. This sampling method was deemed appropriate also because reaching breast cancer patients may have been difficult during the extraordinary atmosphere created by the Covid-19.

In qualitative studies on patient experiences, the sampling needs to be chosen to adequately allow for the representation of varied experiences of patients and their diverse perspectives of accessing treatment. To incorporate such diversity into the sample, the type of health insurance that the patient used to access treatment was chosen as the main variable. In line with this, 6 of the participants only had GSS provided by the SGK while the remaining 6 used a mixture of GSS and their PHI. In the latter group, half of the patients acquired their PHI through their employers and the other half purchased it individually.

The reason underlying the choice of insurance type as a variable was twofold. First, the existing literature on patient experiences of receiving treatment in PHOPS in Turkey suggests that whether patients have PHI or not might play a determining role in their treatment pathway (Yılmaz, 2020). In the Turkish context, there are two types of PHIs, namely “standard duplicate PHI” and “supplementary PHI”, which are diverse with respect to financing and provision aspects (Hışıl, 2020, p. 61). The prominent differences between the two are such that the former has a kind of scheme in which healthcare spending is covered to a certain extent within the coverage plan and it is possible to utilize it without GSS coverage whereas the latter entails a compulsory GSS coverage and covers the additional payments arise in PHOPS (Hışıl, 2020). In this study, all 6 participants held standard duplicate PHI, and those who obtained supplementary PHIs were not included.

Second, despite the fact that patients solely using GSS correspond to a much wider social segment (although it is not known whether this general trend in accessing breast cancer treatment is manifested in the same way) since the number of PHI uptakes is still low amongst the population (Sigorta Bilgi ve Gözetim Merkezi, 2020), the uptake for PHI still manifests an increasing trend in recent years (Hıışıl, 2020). Indeed, the distribution of the number of PHIs sold in the country displays that the largest number of policies are sold in Istanbul to the extent that “the share of PHI members in Istanbul to those in Turkey exceeds the share of the population in Istanbul compared to the population of Turkey” (Hıışıl, 2020, p. 45). Given that the fieldwork of this research was to be conducted in Istanbul, it was an inevitable opportunity for examining the ways in which the insurance status of breast cancer patients influences their experience of access to treatment. Hence, I have deliberately constructed the sample in this way in order to answer the research questions of this thesis. In this context, it was meaningful within the logic of qualitative research that those who have PHI were given as many places in the sample as those who only hold GSS.

Breast cancer patients who use different PHOPS for their treatment were included in the study. In total, the participants commented on their experiences in 20 different PHOPS based in Istanbul. While some of the participants completed all of their treatments in these hospitals, some others received only a certain part of their treatment from PHOPS and completed their treatment in public hospitals. Turkey implements a cap on co-insurance for services provided by PHOPS. However, standard breast cancer treatment is an exception, as PHOPS are not legally permitted to charge any co-insurance from cancer patients.

Table 1. Profiles of the Patients in the Field Study

Interviewees	Age	Profession	Insurance Type
Patient 1	29	Researcher	GSS-only
Patient 2	42	Textile Retailer	GSS-only
Patient 3	35	HR Specialist	GSS and PHI
Patient 4	62	Retired	GSS and PHI
Patient 5	53	Retired	GSS and PHI
Patient 6	26	Lawyer	GSS-only
Patient 7	57	Civil Servant	GSS-only
Patient 8	52	Manager	GSS and PHI
Patient 9	42	Salesperson	GSS and PHI
Patient 10	53	Retired	GSS and PHI
Patient 11	57	Retired	GSS-only
Patient 12	37	Chef	GSS-only

1.3 Data analysis

This study relies on an exploratory thematic analysis of 12 semi-structured interviews with breast cancer patients. My goal as the researcher was to identify important and engaging patterns in the data, as suggested by Braun and Clarke (2006), and interpret and make sense of them in relation to the research questions of this thesis. The analysis of the data mostly incorporated capturing themes and patterns relevant for the research questions via numerous encodings, which were then grouped with respect to potential responses to those questions. While inductive coding was mostly used throughout the analysis as the majority of themes and sub-themes inductively emerged from the patient narratives, deductive coding was also employed as some of the codes were defined based on the discussions from the

existing literature. In other words, the analysis here adopts a blended approach to coding.

1.4 Outline of the chapters

Upon following the introductory chapter, Chapter 2 presents a comprehensive review of two streams of the literature. The first focuses on healthcare system typologies and sheds light on the hybridization trend that has blurred the public-private dichotomy regarding healthcare system organization in the last decades. The second centers on the literature on patient pathways and offers a detailed examination of breast cancer patient pathways in various healthcare system contexts. Chapter 3 sets the background for answering the research questions of this thesis. Three consecutive subsections respectively provide insights into the Turkish context in relation to the healthcare system structuring before and after the 2003 reforms, the diagnosis, and treatment of breast cancer, and finally, the needs, experiences, and expectations of breast cancer patients. Chapter 4 offers the analysis of the interviews conducted with female breast cancer patients and presents two patient pathways that emerged from the analysis, insured and underinsured pathways, and it accounts for the determinants and implications of these two pathways in terms of accessing quality medical care. Chapter 5 discusses the findings of this study in terms of their significance to the existing literature.

CHAPTER 2

A CRITICAL REVIEW OF THE LITERATURE ON HEALTHCARE SYSTEMS AND PATIENT PATHWAYS IN BREAST CANCER TREATMENT

Guaranteeing people's access to affordable healthcare has become a global policy target with the SDGs (United Nations [UN], 2015). Changes in healthcare systems, however, do not always correspond to this policy target. Overall, the literature on healthcare system typologies points to a trend towards hybridization (Dragoonis, 2009; Reibling et al., 2019; Rothgang et al., 2005, 2010). However, how the hybridization of healthcare systems has shaped the experiences of patients in accessing treatment is an underexplored area.

The New Public Management (NPM) paradigm, which had gained prominence in global policy circles in the post-1980s was influential in the aforementioned healthcare reforms. It attributed a more significant role to the private sector in the organization of healthcare systems, thus blurring the former public-private boundaries in healthcare financing, provision, and regulation. Particularly in terms of the provision of healthcare, the introduction of the PPS in publicly funded healthcare systems has led to the creation of an internal market where private hospitals that offer publicly funded services increasingly became the predominant healthcare providers. Yılmaz (2020) argues that in a poorly regulated setting, this results in problematic patient experiences in terms of access.

The examination of patient experiences in accessing treatment is all the more important for understanding the impact of macro-level changes on the micro-level. In this regard, studying the experiences of specific patient groups, such as patients with breast cancer, is of particular significance because what the internal market model

offers may not always serve the best interest of those patients and thus fail to fulfill their varied needs. This thesis aims to uncover whether there are prominent issues with accessing services that are covered universally such as cancer treatment. To this end, it explores the experiences of breast cancer patients in accessing treatment in PHOPS in an internal market setting in the Turkish healthcare system.

This chapter is divided into three consecutive parts. The first will delineate the main characteristics of healthcare systems utilizing healthcare system typologies. It will reveal how the organization of public healthcare has changed over time and how the role of the private sector in healthcare provision has gradually increased around the world. The second will elaborate on the major healthcare reforms in Turkey starting from 2003, which granted the state a new regulatory role in the organization of healthcare. It will also discuss how the state's new role in an internal market for healthcare provision affects the publicness of healthcare services. After highlighting the differences between coverage and access in healthcare, it will introduce Yılmaz's (2020) framework for analyzing patient experiences in accessing treatment, which forms the basis for the conceptual framework of this thesis. The third will describe patients' treatment pathways with a particular emphasis on the notion of patient choice in healthcare and present the existing literature on the treatment pathways of breast cancer patients in various healthcare systems.

2.1 An introduction to healthcare systems in the past and present

Healthcare systems form “the institutional basis and expression of health policies” (Mackintosh & Koivusalo, 2005, p. 5). It is therefore necessary to lay out the general characteristics of healthcare systems, which also helps to contextualize how the organization of public healthcare has responded to the “welfare state crisis” (Offe,

1984) that appeared in the 1970s and particularly how the private sector has become prevalent in the provision of healthcare around the world. In this respect, healthcare system typologies reflect the complex interplay between the finance, provision, and regulation aspects of healthcare that laid the foundations for the structure of new interrelationships between the public and private actors.

The previous and current healthcare systems in Organization for Economic Co-operation and Development (OECD) countries manifest considerable differences due to their changing economic, political, and social prospects. Thus, there is ample literature on the healthcare system typologies (Bambra, 2005; Burau and Blank, 2006; Böhm et al., 2013; Moran, 2000; OECD, 1987; Reibling, 2019; Wendt et al., 2009; Wendt, 2009, 2014). One of the leading typologies is a 1987 OECD study that introduced three basic models, taking into account all three domains of healthcare systems: financing, service provision, and regulation.

The first model, the National Health Service (NHS), is marked by universal coverage, financing through general taxation, and public ownership and/or control of service provision (OECD, 1987). The prevalent examples of this model at the time were the United Kingdom (UK), New Zealand, and Sweden. All three countries have since shifted away from this pure model (Burau and Blank, 2006).

The second is the social health insurance model, which is characterized by compulsory universal health coverage as part of a broader social security system, meaning that healthcare is funded by non-profit insurance funds based on employer and employee contributions and service provision can be both public and private (OECD, 1987). Germany, the Netherlands, and Japan were pioneering users of this model.

The third is the private health insurance (PHI) model, which is characterized by a system in which healthcare is financed through individual procurement or employment-based private insurance, service delivery is vastly private in ownership, which is certainly associated with the United States (US) (OECD, 1987).

Although the 1987 OECD study explicated the different roles of the state and its degree of involvement in healthcare services vis-à-vis the market, the accuracy of this classification has been disputed in the literature. This is because, like most social systems, healthcare systems have been complex, dynamic, and adaptive to change (Plsek & Wilson, 2001), which renders them to be difficult to compare. Reibling et al. (2019), for example, stress that there has been an immense hybridization of healthcare systems after successive healthcare reforms. Nevertheless, it is important to note that the 1987 OECD typology is still useful for presenting the complex relationship between the financing, provision, and regulation of healthcare services, and new configurations of interrelations between public and private actors in these elements of healthcare systems.

Healthcare systems under transformation

From the early 1970s onwards, the global economy has undergone a major economic crisis that has led to steadily growing inflation and budget deficits in the public sector. The changing economic conditions were hampered by the oil crises, which had an immense impact on the functioning of the global economic system. The period of economic recession in the aftermath of the oil crises, especially in the post-1980s, coupled with the aging population, brought about a collection of cost-containment measures regarding welfare provision in general and healthcare systems in particular due to its significant consumption of public budget (Culyer, 1990). To

illustrate the significance of these measures for the healthcare sector, Moran (2000) expresses that “No policy area has been more dominated by the search for cost containment since the end of the long boom” (p. 156). This posed a great challenge for the healthcare systems in the welfare state contexts because, as Rothgang et al. (2005) succinctly puts, “the legitimacy of health systems [in these countries] is largely based on their capability to provide a satisfactory standard of healthcare for all citizens, irrespective of their ability to pay for it” (p. 188).

Moreover, the critics of the public sector in social services have proposed that the public sector fails to bring efficiency and is not responsive to patient demands. The private sector is portrayed far more responsive to patient demands due to increased competition amongst service providers, which is anticipated to not only enhance patient choice but also surmount inefficiency and corruption (Rosenthal & Newbrander, 1996). They have argued that the public sector does not have enough stimuli to operate efficiently since the objectives of publicly controlled organizations are most of the time pervasive and irreconcilable (Tynkkynen & Vrangbæk, 2018). In addition, the public sector is not accountable to shareholders or owners, which makes it less exposed to outward pressure in terms of pursuing technological advancement and innovation (Tynkkynen & Vrangbæk, 2018). In other words, the fact that the public sector does not carry the risk of bankruptcy allows it to provide services at sub-optimal levels (Alonso et al., 2013, Kornai, 2009).

Alongside these factors, increasing patient choice in healthcare was one of the major drivers of the transformation of healthcare systems (Basu et al., 2012). Therefore, the diversification of healthcare services in terms of available treatments and service providers as opposed to a standardized healthcare provision for all by the public sector was thought to allow for greater patient autonomy. As such, rendering

patients as consumers and empowering them with choice was viewed as a solution for inefficient resource allocation (Fotaki et al., 2005). Besides, public services where little or no choice was offered were expected to result in significant health inequities as well (Le Grand, 2006).

In the context of healthcare system changes, Rothgang et al. (2005) investigate whether the three aforementioned models (OECD, 1987) have converged or deviated from one another. They find that in terms of financing, there has been a decreasing trend in the share of public health expenditure as opposed to private in total health expenditures, which indicates an increased private involvement in finance for all three. Changes in provision could not be examined due to limited data in this domain (Rothgang et al., 2005). As far as regulation is concerned, there has been a general propensity to incorporate such unfamiliar modes of coordination into each type. Precisely, market competition and negotiation through internal markets were introduced in the NHS-type and to some degree in the social health insurance type, and a sort of hierarchical regulation was established in the PHI-type.

In light of these findings, Rothgang et al. (2005) point to an overall transition from pure models to mixed (or hybrid) types of healthcare systems. The increasing prevalence of mixed types brings into view the question of whether the private provision of healthcare services in tax-financed and state-regulated healthcare systems generates desirable outcomes in terms of patients' access to treatment. Some suggest that this type of organization is congruent with the principles of UHC and equality in accessing treatment, which is especially relevant for countries where the pure public provision of services has become a growing difficulty (Rothgang et al., 2010). Others argue that the hybridization of healthcare systems might indeed pose a challenge to guaranteeing all-inclusive and free-of-charge healthcare services

(Dragoonis, 2009). In this respect, this thesis seeks to provide an answer to this question in the context of breast cancer patients' access to treatment in Turkey.

Böhm et al., (2013) offer a healthcare system typology that identifies five contemporary healthcare system types based on the data from 30 OECD countries. This typology demonstrates the continued relevance of three models introduced in the 1987 OECD study and introduces two novel types including the National Health Insurance and the Etatist Social Health Insurance models. In the NHI model (e. g. Canada, Australia, and Italy), the delivery of services is contracted out to private for-profit providers, which differentiates it from the NHS system (Böhm et al., 2013). The Etatist Social Health Insurance model (e. g. Belgium, Hungary, South Korea, and the Netherlands) is very similar to the social health insurance model as it leaves funding and provision to the market, but the state plays a more important regulatory role in the former (Böhm et al., 2013). The important difference between the former (OECD, 1987) and the latter (Böhm et al., 2013) classifications is the increased presence of private sector involvement in financing and providing healthcare, which is consistent with the findings of Rothgang et al. (2005, 2010) regarding the public-private dichotomy.

2.2 The blurring public-private boundaries in healthcare systems

The 1970s and 80s were a period of radical transformations. The global economic order had been deteriorating due to extensive budget deficits, which resulted in a general atmosphere of austerity regarding welfare state institutions (Jessop, 1999). Not only the conservative parties that have risen to power but also their center-left counterparts followed such an agenda that leaves behind the national-developmental strategies and replace them with “a new post-national mixed

economy” where partnership and networks between different public and private agents have become paramount (Jessop, 1999, p. 356).

In that atmosphere, the Keynesian premise that increased state interference was necessary for economic development and prosperity was subject to fervent criticism, the vast majority of which came from the Chicago school of economics. In addition, all institutions that maintain a Keynesian economic model were considered inefficient (Gough, 1987). Given these circumstances, the governments were compelled to take prompt cost-containment measures, which rendered the provision of and continued investment in public services all the more challenging (Abel-Smith & Mossialos, 1994). In this new era, increased spending was not perceived as an issue as long as it was not from the public budget (Hermann, 2010). As a result, it was the market in lieu of the state that began to be viewed as a facilitator of economic development and prosperity. Towards that end, many governments have resorted to the private sector particularly in the financing and provision of public services (Anderson, 2012; Maynard, 1986; Zheng et al., 2008).

2.2.1 New public management

The traditional public-private sector dichotomy has increasingly become nebulous in the post-1980s conjuncture, which inaugurated novel forms of public service provision based on the business theories and practices that largely originated from the New Public Management (NPM) paradigm (Durán & Saltman, 2015). The preliminary developments of this peculiar management concept took place in the UK in the late 1970s onwards under Prime Minister Margaret Thatcher as well as in some states in the US on a state level where the economic recession hit the hardest (Groot & Budding, 2008), which further spread through different parts of the world

in the following decades (Lane, 2000; Pollock et al., 2004). Overall, the implementation of NPM reforms diverges greatly from one country to another (Hood, 1991), which renders them a contextual character.

The rationale behind mixing public and private sector management practices originated from the pro-market perspective that a bureaucratic top-down organization was not responsive to the demands emerging from the society (Le Grand, 1999). Although both of these sectors encompassed similar managerial tasks, the latter's competence and aptitude were considered superior to that of the former (Ranade, 1994). Those who endorsed the NPM doctrine insisted that non-competitive public service provision not only jeopardized the free choice of patients but also caused an inefficient allocation of resources with low-quality outcomes (Rhodes, 1994). In that respect, the reform proposals in the management of public services were legitimized based on the rhetoric of cost containment, better use of resources, increased efficiency and effectiveness, innovation, and value for money (Rhodes, 1994). This rhetoric alone indicates that the market ideology has been the greatest influence in laying the groundwork for a new comprehensive reform agenda for public service management, particularly in the healthcare sector due to the burden it places on the public budget. On top of that, the proponents of patient choice also proposed that if the marketization is adequately planned in such a way as to support those who are less able to make informed choices as well as to revoke incentives to cream-skim patients, widespread availability of choice in healthcare provision may even generate equity in terms of service use and equality of choices (Barr et al., 2008; Le Grand, 2006).

2.2.2 NPM in healthcare

The definition of the private sector in health care is still vague. Clarke emphasizes that the absence of a comprehensive international legal framework for defining private sector involvement in public services rendered this concept to be used erratically (2014, pp. 4-5). For this reason, Hallo de Wolf and Toebees argue that it is more accurate to pursue what private sector involvement in healthcare might entail instead of a concrete definition because it is not a “passive concept but an actual state of affairs” (2016, p. 80). The participation of the private sector thus covers a wide array of activities such as the governance of healthcare institutions, the provision of healthcare services alongside the manufacturing and/or financing of healthcare goods. The meaning of the private sector also changes across contexts as it may refer to diverse types of non-state actors in the healthcare sector, including multinational companies, non-governmental and non-profit organizations as well as private individuals, such as general practitioners and consultants (Wolf and Toebees, 2016).

Le Grand et al. (1992) present a comprehensive account of state interference in healthcare in the following manners: direct provision, finance through tax and subsidy policies, and/or regulation. In line with this, one can observe that when the presence of private providers proliferates, it does not necessarily mean that direct privatization has taken place. In some cases, private providers could either directly receive a subsidy from the state or they could be an integral part of social insurance or NHS systems (Le Grand et al., 1992). An example of this is the public-private partnership in the UK undertaken in the form of the PPS, which is also similar to changes in the Turkish healthcare system, albeit to a certain extent.

Ağartan (2019) succinctly summarizes the central elements of the NPM paradigm in the healthcare sector as follows:

the renewed focus on improving efficiency and accountability through (i) disaggregating large public sector bureaucracies, reducing organizational hierarchies and expanding new management systems for monitoring and evaluating professional work, (ii) encouraging competition through a purchaser-provider split and expanding contractual relationships with public and private providers, and (iii) introducing new payment and incentive mechanisms that reward performance defined and measured in new ways. (p. 1412)

All these aforementioned elements play a significant role in the transformation of healthcare systems and are thus worth scrutiny. However, the PPS results in such a crucial structural change in healthcare systems, which is all the more relevant for the research question of this thesis and should therefore be discussed in more detail.

The PPS is a model of service delivery that aims to transform the previously centralized and highly bureaucratic healthcare provision by separating third-party payers from service providers (Tynkkynen et al., 2013). In other words, it can be defined as the separation of “the purchaser, as the agent who decides what will be produced, from the provider, as the agent who delivers the agreed outputs or outcomes” (Ryan et al., 2000). One of the central functions of PPS is to establish competition amongst providers, be it public or private. Competition is viewed as an adequate way of guaranteeing “best value for money spent” (Davidson, 1999, p. 161) and improving service quality since the providers need to allure as many patients as possible to maintain financial sustainability in what Le Grand (1991) coins as the “quasi-market” model. In congruence with this, Lapsley argues that in this quasi-market model, “efficient hospitals should gain; inefficient hospitals may lose contracts and decline or even cease to exist” (1994, p. 20). However, to what extent economic efficiency goes hand in hand with responsiveness to patient demands is an

open question. For instance, Grout (1997) states that the remuneration of private providers for successful service delivery renders them behave in such a way as to prioritize cost-containment instead of service improvement in the long run. Moreover, the maintenance of excess capacity deemed necessary for competition carries a sizable risk of generating a supplier-induced demand, thus creating an industry that handles pre-authorized treatment and constant review of service usage, which creates extra costs with a comparatively low marginal benefit to patients (Edwards, 2005).

The practice of outsourcing clinical services also influences the conduct of private providers. This is because in certain sectors, such as the medical device and equipment sector, outsourcing enables the private providers to have a great voice over which medical device or equipment is a high priority and which are not, thus engendering new investment opportunities for private enterprises and “the diffusion of medical technologies that are expected to be profitable” (Blank, 1996, p. 332). The issue is such that the decisions of these private actors may not always be suitable for better public healthcare outcomes. In this regard, whether the privatization of both clinical and non-clinical healthcare services generates undesirable consequences depends heavily on the extent to which the state can control and regulate the workings of the private providers (Checkland et al., 2009).

2.2.3 Regulation in healthcare in the context of an internal market

The National Health Insurance systems with a demand-side model of cost-sharing have been particularly promoted by the World Bank and the International Monetary Fund to alternate the supply-side cost-containment strategies of the NHS systems (Fox and Reich, 2015). Many of these governments have implemented in their

healthcare systems a quasi-market structure where healthcare service provision takes place within a competitive market that grants patients the ability to choose their service provider, which is regulated by the state to overcome inequalities (Le Grand and Bartlett, 1993). In this context, internal markets were considered as “a possible way of retaining a system of finance which secures the macro-objectives of cost containment and equity but incorporating within that system micro-incentives for efficiency and consumer satisfaction” (Bevan, 1989, p. 53). The literature demonstrates that the creation of internal markets in the provision of services by way of market-oriented reforms has intensified the integration of public and private sectors (Øvretveit, 2003; Saltman, 2003). Consequently, this brought about novel challenges for the state in terms of “both legislative and regulatory oversight of the healthcare system” (Jacobson, 2001, p. 1166).

In this regard, a new emphasis has been placed on state regulation over the market activities in the literature (Helderman et al., 2012; Majone, 1994; Rothgang et al., 2005; Schmid et al., 2010; Van de Ven et al., 2013). In light of this, Denis et al. (2015) argue that the regulatory framework in hybrid healthcare systems at different levels and from diverse standpoints of providers, regulators and patients warrant a more in-depth examination. Yılmaz concomitantly argues that the regulatory role of the state is crucial for “ensuring compatibility of private sector profit-seeking motives with the UHC ethos of publicly-funded healthcare systems” (2020, p. 2).

Whether and to what extent regulation can work in hybrid healthcare systems has also been contested in the literature. Some studies present a cynical view on the effectiveness of state regulation of private sector activities. For instance, Jacobson et al., (2011) underline how the US systematically fails in regulating the healthcare sector despite its historically remarkable regulatory capacity and how this poses

considerable challenges for access. On the other side, Van de Ven et al. find that although implementing state regulation is complicated, it could still be attained if certain preconditions are fulfilled such as “free consumer choice of insurer, cross-subsidies without opportunities for free riders and guaranteed access to basic care” (2013, p. 243). In congruence with the latter view, Helderma et al., (2012) assert that regulation is necessary for it to ascertain the convening power of the government against the organized interests of the private agents. However, they also emphasize that regulation strategies ought to tackle numerous issues in a continuously more complex configuration of third-party payers and service providers, functioning at multiple levels of the healthcare system (Helderma et al., 2012).

The regulatory capacity of states is especially significant in terms of the rapport between service users and providers. Taylor-Gooby (1999) asserts that a regulatory framework that establishes a relationship based on trust between users and providers is indispensable for healthcare markets to function properly. To put it in his words, Taylor-Gooby (1999) elucidates the role of trust as follows:

Individuals who trust each other are better equipped to reduce the transaction costs involved in the detailed and continual checking of contract compliance and can invest in the future with greater confidence that obligations will be honored. Thus, the benefits of egoistic rationality may best be realized when it is accompanied by its contrary. Governments cannot legislate for trust directly, but they may be able to encourage its growth and penalize self-interested defections from trust. (p. 103)

This is especially relevant for healthcare services because patients are prone to suffer from information asymmetry, which reduces their capacity of setting their preferences and needs prospectively (Arrow, 1963). In this respect, the notion of choice aforementioned earlier in this section when introducing the critiques of the public service provision should be reconsidered. That is to say, contrary to the rigid

understanding of choice as an economic behavior proposed by the rational choice theories, the notion of choice is a seemingly “fluid, complex and socially conditioned” (Taylor-Gooby, 1999, p. 101) notion, which is affected by the specific circumstances of the decision-maker. It can therefore be deduced from Taylor-Gooby’s (1999) account that choice is meaningful only if there is a trustful rapport between service users and providers in an increasingly marketized environment, which facilitates tackling information asymmetry on the part of the former as well as confining potential acquisitive behaviors of the latter. Otherwise, increased locus of patient choice and economic incentives of service providers together may result in the latter’s selective treating of patients in such a way as to prioritize the wealthier, healthier, and better-educated clients (Blomqvist, 2004).

To sum, the establishment of the PPS as part of healthcare financing, which in turn generated an internal market in the context of healthcare provision has generally resulted in the blurring of public-private boundaries. Even though the implementation of market principles marginalized the state’s role as the main provider of healthcare services, the state’s regulatory role has thus far maintained its prominence.

2.2.4 The publicness of healthcare in the context of an internal market

The regulatory framework of the state has become a new research domain for studying publicness in healthcare systems (Yılmaz, 2020). Yılmaz (2020) asserts that in principle, internal markets do not appear to threaten the publicness of healthcare services but in reality, they might pose a danger to “realized publicness” (Moulton, 2009). This concept is defined by Moulton (2009) as “the realization of public values demonstrated by organizational behavior or outcomes” (p. 891). Dwelling on

Moulton's (2009) concept, Yılmaz (2020) states that this way of viewing publicness exceeds the macro-level indicators such as the extent of the public sector on the grounds of finance and ownership and appertains to the extent to which private organizations aim for public sector goals and outcomes at the micro-level.

One gateway into the micro-level is to examine the access dimension. Taking into account that this thesis focuses on breast cancer patients' access to healthcare services, it is necessary to offer a brief overview of the notion of access as it is discussed in the literature. The definition of access is discussed in the literature in a contested way (Lisac et al., 2010), which indicates the complexity of defining access. Busse et al. (2006) assert that a widespread definition of access in healthcare entails that a standard quality of healthcare services is provided for all irrespective of one's ability to pay or social standing. To provide a more nuanced account, Roberts et al. (2008) delineate access as follows:

First, "access" sometimes simply refers to whether services are offered in a specific area. Here, the question is physical availability, which can be measured by the distribution of available inputs (beds, doctors, or nurses) compared to the population. A second notion, one that more closely reflects the intuitive meaning of the term, is effective availability; that is, how easy is it for citizens to get care? Differences between physical availability and effective availability can arise because various barriers (e.g., cost, travel time, poor service) may keep people from using facilities that are physically available. (p. 114)

To elaborate on the subtlety between physical and effective availability in terms of access, Lisac et al. (2010) account for access in the form of three overriding dimensions, namely availability, reachability, and affordability of healthcare services. Availability broadly refers to the institutional and infrastructural capacity of the system, be it the number of healthcare providers or medical personnel; reachability is related to the physical aspect of access as in the geographical

distribution of hospitals, medical equipment, or health workforce; finally, affordability concerns with financing such as insurance arrangements or the reimbursement of healthcare services (Lisac et al., 2010).

Given these accounts, the relationship between coverage and access can be expressed in such a way that the existence of the former does not guarantee the successful acquisition of the latter. The following studies, which I will present below, demonstrate that access to treatment is still an actual issue for some groups of patients even in countries with strong service coverage and public financing. This is especially true for patients who need specialist services and/or patients with NCDs such as cardiovascular diseases, diabetes, and/or cancer.

Even though the existing literature revolves around obstacles to patients' access to treatment in the context of under-resourced healthcare systems, the consideration of a country as having realized UHC does not always necessarily result in leveling the conditions of patients on equal grounds in other settings. The hybrid healthcare system in Turkey, which is at the core of this research, constitutes an illustrative case to investigate this issue. The introduction of the GSS scheme fulfilled the requirements for achieving UHC in Turkey. This was accomplished at the expense of establishing an internal market for healthcare provision in which private providers become increasingly prominent in below-par regulated conditions, which culminated in problematic patient experiences of accessing treatment (Yılmaz, 2020).

How the influence of the internal market model for healthcare provision in publicly funded systems on access shapes patients' experience of accessing services is thus far underexamined. However, this new institutional configuration is worth the examination in terms of the extent to which it enables a system where

competitiveness and publicness may coexist. For this purpose, Yılmaz's (2020) framework for analyzing patient experiences in their ability to receive treatment in a hybrid healthcare system informs the conceptual framework of this thesis. His research explores the ways in which patient experiences and access conditions are shaped by the establishment of internal markets and how the implementation of an internal market in the new hybrid healthcare system in Turkey as a macro-level change has influenced patient experiences in accessing treatment in PHOPS at the micro-level.

Yılmaz (2020) focuses mainly on the affordability dimension and situates its findings within the literature on informal payments in healthcare in developing countries (e.g., Balabanova and McKee, 2002; Ensor, 2004; Lewis, 2007; Tatar et al., 2007; Vian et al., 2006). Yılmaz (2020) finds that patient experiences with PHOPS are multifaceted and indicates that while patients with non-emergency conditions seldom had problematic experiences, those with chronic or rare diseases and those with complex and acute conditions made significant amounts of informal payments for services that they were entitled to as a consequence of the private provider's stratagem in the context of failed public regulation.

Yılmaz's (2020) analysis of patients with negative experiences in accessing treatment in a hybrid healthcare system demonstrates that "information asymmetry between patients and PHOPS, manipulation strategies of private providers, and the lack of effective public regulation" (p. 9) are the main factors that hinder patients' enjoyment of their entitlements and thus the realization of publicness.

2.3. Patient experiences in accessing treatment in hybrid healthcare systems

Hybrid healthcare systems where there is a compulsory National Health Insurance scheme provide patients with the opportunity of choosing between public and private healthcare providers. In this regard, patient autonomy has been adamantly promoted by the proponents of hybridization in the healthcare sector. However, these macro-level changes in the organization of the healthcare system may not fully correspond to patient experiences at the micro-level in their pathways to treatment in hybrid healthcare system contexts.

2.3.1 Patients' treatment pathways

Particularly for NCDs such as cancer, patients are more eager to collaborate with the healthcare providers throughout the whole treatment process so that they can ameliorate their healthcare experience (McColl-Kennedy et al., 2012). Despite that patient autonomy and patient pathways have gradually become a more attractive research area in healthcare, the existing studies largely focus on the healthcare pathway from a medical perspective (Cherif et al., 2020) and the number of studies concentrated on the patient experience of the healthcare delivery is still sparse (Rapport et al., 2019; Tremblay et al., 2015).

Victoor et al.'s (2012) study on the determinants of patient choice of healthcare providers underlines that choice is governed by "a complex interplay between patient and provider characteristics" (p. 11). These characteristics significantly impact whether or not patients make decisions, are motivated and able to choose as well as how they choose, therefore, the "typical patient" does not exist since different patients make distinct choices depending on their varying circumstances (Victoor et al., 2012, p. 13). Another important finding of Victoor et

al. (2012) is that comparative information regarding provider characteristics impact patient choice only to a limited degree. These findings demonstrate that the existing literature on health policy may oversimplify patient choice and there are still considerable gaps of knowledge that entail further research in this area.

Mosadeghrad (2014) identifies eleven factors that influence patients' choice of the service provider, namely "service type, hospital, word of mouth (recommendation), cost, patient's medical insurance program, location, physical environment, facilities, providers' expertise, providers' interpersonal behavior, and hospital reputation" (p. 161). On top of these factors, the severity of illness appears as the most prominent determinant of patient choice because, in such emergencies where any delay would result in devastating health outcomes, including death, patients may not be in a position to take into account the cost, accessibility and even the quality of services (Mosadeghrad, 2014). Moreover, the aspect of choice when it comes to service providers constitutes a considerable burden for patients with long-term conditions for the time spent in research and selection of the most appropriate provider, and a constant switchover between providers may threaten the continuity of care (Edwards, 2005).

Granting these accounts, this thesis considers the investigation of patient pathways to treatment as a fruitful area of inquiry for researchers who aim to understand the effects of macro-level transformations on the micro-level. Examining the experiences of particular patient groups, such as breast cancer patients, is especially suggestive in that what is offered in the internal market for healthcare may not always comply with the best interest of cancer patients, thus causing their varying needs to remain unmet. In other words, the competitive nature of the internal market may work towards the fragmentation of oncological care and thus endanger

integrated and continual treatment, which are pivotal for patients with long-term conditions (Schers et al., 2002).

Congruent with this, the literature on patient pathways both in general and for particular diseases has increased over the last decade (Richter & Schlieter, 2019). The concept of the patient pathway is defined in multiple ways, and it is coined in different terms such as patient journey or care pathway elsewhere. This thesis follows the definition of Richter and Schlieter as they characterize the concept as “the actual, unplanned journey of a patient seeking health care services to address her/his health conditions” (2019, p. 993). This definition lends itself well to exploring the varied experiences of breast cancer patients because it does not reduce the concept into a set of standard built-in procedures that determine the course of treatment (Richter & Schlieter, 2019).

The majority of the literature on patient pathways for particular illnesses focuses on oncological illnesses (Richter & Schlieter, 2019). This shows that patient pathways have increasingly been recognized as a useful approach to cancer treatment for it facilitates the communication with patients, the establishment of integrated care as well as better planning and implementation of medical guidelines thanks to its stronger focus on the individual patient (Albrecht et al., 2017). Even though Lismont et al. (2016) suggest that patient pathways are highly peculiar, the recent literature in the field of oncology and patient pathways reveals that the setting in which cancer patients receive treatment has an influence on their health outcomes (Gaga-Bouchard et al., 2014; Onega et al., 2008; Huang et al., 2014).

In addition, the factors affecting cancer patient pathways in terms of choosing their healthcare provider differ in relation to patients' socio-economic position. Those with higher socio-economic backgrounds are more prone to access multiple forms of

social capital, which grants them the necessary resources, expertise, and social networks when choosing where to receive their treatment whereas patients from the lower social strata are deprived of these possibilities, thus having to follow the referral track proposed by the primary care physician or specialist (Gaga-Bouchard et al., 2014).

2.3.2 Breast cancer patients' treatment pathways

Breast cancer patients are among these patients who need often costly specialist services. A comprehensive cancer treatment incorporates a list of medical interventions that range from specialized diagnostics to surgery, radiotherapy, and chemotherapy (Moye-Holz et al., 2020). Breast cancer is an increasingly widespread, yet treatable disease and it is the most common cancer type amongst women worldwide (Moore, 2007). Several studies have centered on the financial encumbrance of breast cancer around the world (Barron et. al., 2008; Luengo-Fernandez et al., 2013; Jönsson et al., 2016). Indeed, breast cancer treatment constitutes the highest share of healthcare costs across the European Union (Luengo-Fernandez et al., 2007). In developing countries where the healthcare spending is lower, many cancer drugs are not covered, thus leading to extensive out-of-pocket spending as well as restricted treatment options (Fan et al., 2015). In addition, certain treatments such as hormone therapy as well as highly specialized medical professionals such as oncologists might be found only in a certain hospital in many low-and-middle-income countries and regions (Harford et al., 2008).

The timing of access to healthcare is also a significant factor in breast cancer. This is because early diagnosis and treatment have a positive impact on the rates of survival (Brooks, 2009). However, most of the time patients are obliged to roam

amongst multiple services provided in different locations, especially in the healthcare systems of developing countries. This is important to highlight because any amount of time wasted due to disorganized service navigation might hamper patients' ability to receive treatment for months or even years (Agarwal et al., 2007). As a result, accessing treatment for breast cancer patients is often possible through a process of countless health encounters at a distance and with significant expenses (Smith et al., 2006).

Moreover, despite major improvements in cancer treatment and the fact that it has increasingly been included in essential service coverage across the world, this progress has come at a price (Schoen et al., 2011). The increasing number of available treatments and new technologies used in healthcare open the door for ever-rising healthcare costs, which patients are expected to contribute either through increased out-of-pocket expenses or growing copayments and coinsurances, thus causing financial hardship for cancer patients (Goldman et al., 2007).

Patients who possess some sort of insurance but still have to contribute to the treatment costs by out-of-pocket payments are considered underinsured (Schoen et al., 2011). The extent of financial hardship regarding cancer treatment has a negative influence on the well-being of underinsured cancer patients, let alone the uninsured (Zafar et al., 2013). This is especially significant in terms of many generic and originator cancer medicines, which are often unaffordable for patients and even some governments in low-and middle-income developing countries (Siddiqui & Rajkumar, 2012). In cases where cancer medicines fundamental for treatment are either unavailable and unaffordable, treatment is either unsatisfactory or fully disrupted, thus resulting in devastating health outcomes (Knaul et al., 2011). Hence, equity in access and affordability of essential medicines is indispensable for cancer treatment

(Lopes et al., 2013) but it is hard to achieve for low-and middle-income countries due to their high costs.

Alongside financial hardship, the literature reveals that cancer patients are faced with ongoing information needs both before and after diagnosis and treatment, which most of the time remain unmet (Blödt et al., 2018; Cebeci et al., 2012; Landmark et al., 2008; Partlak Günüşen et al., 2013; Tompkins et al., 2016). Receiving necessary information can be considered as part of accessing treatment. The role of information is crucial in that it reaches far beyond the initial decision-making processes regarding treatment, and it is used as a persistent management tool, which helps patients to evaluate their situation in a constant state of uncertainty (Blödt et al., 2018).

In addition, Landmark et al.'s (2008) assert that medical information about cancer is less important as opposed to how that information is shared in the eyes of patients, thus emphasizing the distinction between information as a procedure and a process. They argue that the latter should be adopted by healthcare professionals so that patients can transfer information into meaningful knowledge (Landmark et al., 2008). In light of these issues, the importance of abiding by the patient's perspective (Sepucha et al., 2006) in the context of cancer becomes all the more apparent. It is therefore appropriate to argue that breast cancer patient experiences deserve a more nuanced analysis.

In this regard, Cherif et al.'s (2020) study introduces different stages (the discovery stage, examination stage, and survivorship stages) and dimensions (the medical, cognitive, and relational dimensions) of patient pathways to treatment. They argue that while the existing research stresses the medical and clinical perspectives from which several technical and informational concerns emerge, patients diagnosed

with breast cancer experience the treatment process very differently from an experiential perspective. Cherif et al.'s (2020) findings demonstrate that at the initial stage, most breast cancer patients solicit support that they struggle to receive from physicians and nurses. They feel the need to be embosomed by those who sympathize with their distress when they encounter a deficit of information, at least in part due to exiguous dialogue and listening, which causes problems of misunderstanding at all stages of the treatment pathway (Cherif et al., 2020). In these situations, breast cancer patients endeavor to locate the information apart from the medical personnel, which proffers that the medical dimension (professionalism, expertise) is “only one component among others in determining the patient pathway and in particular those related to cognitive (request and transmission of information) and relational (empathy, support) dimensions of the experience” (Cherif et al., 2020, p. 8).

The literature on breast cancer patient experiences in accessing treatment in different healthcare systems is nascent (Dye et al., 2010; Grosse Frie et al., 2018; Mousa et al., 2011). These studies highlight that patient pathways are diverse depending on the specific healthcare settings in which patients access treatment.

Breast cancer patient pathways are mediated by the healthcare systems of the countries they live in (Anderson et al., 2006). For instance, Mousa et al. (2011) studies the patterns of seeking treatment amongst Egyptian women diagnosed with breast cancer and argues that “patient-mediated factors, health providers’ factors, and/or barriers in the healthcare system” (p. 555) influence patients’ ability in receiving treatment. They argue that several factors related to healthcare providers and problems specific to the healthcare system are less studied in the literature compared to patient-mediated factors. Therefore, Mouse et al. (2011) study system-

mediated factors for the first time and assert that even though patient-mediated factors play a considerable role in late diagnosis, many obstacles related to the healthcare system organization are also crucial because they ultimately form barriers to access even in situations where patients are informed enough to pursue an early diagnosis.

These barriers include but are not limited to the high cost of cancer management, the restricted capacity of diagnosis and treatment facilities, and unsatisfactory medical education in oncology (Mouse et al., 2011). Due to the combination of these factors, breast cancer patients are not capable of effectively navigating the health care system, which can result in problems with accessing treatment in a timely manner. Mouse et al. (2011) emphasize the inadequacies found in the healthcare system in Egypt, which require a better allocation of resources by the government to reduce barriers to accessing treatment within the healthcare system. Since the implementation of the Universal Health Insurance Reform Act in 2018, Egypt has been considered as having achieved UHC (Mathauer et al., 2018). However, the impact of this on breast cancer patient pathways, as described by Mouse et al. (2011), is unknown.

Grosse Frie et al.'s (2018) qualitative study in Mali examines patient perspectives on the late diagnosis and treatment of breast cancer and unveils that breast cancer patients encounter a number of both personal and health system-related difficulties, which results in disruptions in accessing healthcare. These difficulties involve poor knowledge of breast cancer among patients and medical personnel, financial hardship due to significantly high costs, skepticism regarding the healthcare system as well as the absence of specialized services and mechanisms of social support (Grosse Frie et al., 2018). Their findings also highlight that there is a lack of

information regarding the extent to which breast cancer patients' socio-demographic characteristics are indicative of their choice of healthcare provider. In 2018, the parliament in Mali approved a law on a national universal health insurance scheme, but it has not yet been legislated (Mathauer et al., 2019). The potential impact of this development on breast cancer patient pathways deserves further attention.

Dye et al.'s (2010) study on Ethiopia indicates that understanding how patients diagnosed with breast cancer travel through this numerous and, in many cases, inadequately distributed set of diagnostic and treatment services in health systems is crucial. This is of particular importance in countries such as Ethiopia where unequal access is one amongst many challenges found in the healthcare system (Dye et al., 2010). Their findings suggest that breast cancer patients are understandably hesitant, distressed and scared, or simply incapable of making informed decisions without the assistance of well-trained medical personnel. In spite of the overall advancement in healthcare delivery, Ethiopia still lags behind in terms of UHC according to the UHC index presented by the WHO despite that the government has been working on the implementation of a social health insurance scheme for formal sector workers and civil servants in addition to its community-based health insurance system (Lavers, 2019).

2. 4 Conclusion

This chapter demonstrated that the institutionalization of healthcare under the broader development of the welfare state in Europe paved the way for the emergence of healthcare systems as we know them today. Through an overview of the healthcare system classifications, it presented the main elements of these systems. In addition, it explained not only the ways in which the organization of public

healthcare has responded to the welfare state crisis but also how this process has increased the role of the private sector in healthcare across the world. Drawing from the developments in the last decades of the twentieth century at both national and global levels, it illustrated that the increased prevalence of market mechanisms in the healthcare sector led to the evanescence of the public-private dichotomy and resulted in hybrid healthcare systems.

This has taken place by means of substantial reform processes regarding healthcare under the NPM doctrine, which endorsed the private sector involvement in the organization of healthcare systems. Therefore, the following subsection expressed that the NPM paradigm attributed an important role to the market ideology in healthcare and underlined the altered power dynamics between public and private actors in the provision of healthcare through the introduction of public-private partnerships. Particularly, the introduction of the PPS alongside the practices of contracting out/outsourcing healthcare services was influential in this regard. In line with this, the decreased role of the state in the provision of healthcare and its new regulatory responsibilities were discussed.

This chapter also revealed that the attainment of UHC, which was promoted by the international organizations, has had a drastic domino effect on the efforts of the national governments in healthcare system restructuring. The newly established public-private partnerships and increased market activity in the healthcare sector resulted in the consideration of some countries as having achieved UHC. In some countries, including Turkey, this was achieved through the establishment of an internal market for healthcare provision.

Yılmaz's (2020) study, which inspired the conceptual framework of this thesis to a great extent, finds that in poorly regulated settings, internal markets may

constitute such hazards as informal and/or illegal payments for fully covered services, which is partly due to considerable information asymmetry between patients and service providers, and these obstacles are intensified when patients deal with chronic illnesses such as cancer. These findings suggest that the influence of internal markets on access varies amongst patient groups. This informed the research question of this thesis in a way that prompted the need for analyzing how the internal market impacts specific patient groups' access to healthcare services, such as breast cancer patients.

In light of this, the final section focused on whether internal markets pose particular challenges to breast cancer patients' access to treatment. It examined the experiences of breast cancer patients and underlined the importance of experiential perspective through an account of patient pathways. In what follows, the differences and similarities between treatment pathways of breast cancer patients in various healthcare system contexts are shown. In the light of these two strands of the literature, this thesis examines how the internal market in healthcare shapes breast cancer patient pathways to treatment in the case of Turkey.

CHAPTER 3

BREAST CANCER IN THE TURKISH CONTEXT

Breast cancer is considered amongst the most calamitous and frequent NCDs in Turkey and worldwide (Çakmak et al., 2019). The rampant increase in cancer rates in Turkey since the late 1980s has rendered cancer to become a more apparent illness in Turkish society (Terzioğlu, 2012). Unlike the treatment of breast cancer in its early stages, the treatment in the advanced stages entails far more resources and often results in poorer health outcomes, which emphasizes the importance of early detection and diagnosis with respect to resource preservation and reduced morbidity (Eniu et al., 2006). Late diagnosis has been prevalent in the Turkish context (Ashing-Giwa, 2004). A systematic cancer registry system is paramount for making sound decisions about which type of cancer requires more infrastructure and human resources (Aydın, 2007). Data on the incidence of cancer was not generated for a defined population in Turkey until the early 1990s (Fidaner et al., 2001).

The Izmir Cancer Registry, established in 1992, was the first population-based cancer registry that covered the province of Izmir, Turkey (2.7 million inhabitants in 1993 –1994). It provided information about the incidence and prevalence of breast cancer in women in 1992: 24.4/100,000 and 0.3% respectively (Fidaner et al., 2001, p. 83). Breast cancer incidence for women has continued to rise in Turkey reaching 56.6/100,000 in 2020 (WHO, 2021). Except for highly urbanized cities in the country, mortality rates for cancer were registered neither formally nor systematically until the early 2000s (MoH, 2011). Since 2005, the Turkish Federation of Breast Diseases Societies (*Türkiye Meme Hastalıkları Dernekleri*

Federasyonu, TMHDF) has maintained an active breast cancer registry under the auspices of the National Breast Cancer Registry Program (Özmen et al., 2019).

In Turkey, the distribution of breast cancer incidence varies geographically (Özmen et al., 2019). Karanlık et al. (2006), in a study on 1841 breast cancer patients from the Istanbul University Medical Faculty, demonstrated that 5 years overall survival rate amongst the participants was paralleled with the data observed in developed countries (around 86%) (2006, p. 92). However, Özmen states that this rate was considerably lower in the eastern parts of the country (around 60%) versus the western regions (2008, p. viii). These differences may stem from a lack of breast cancer awareness and information on the part of medical professionals in less developed eastern provinces, which may have led to greater numbers of late diagnoses. A further complication is the uneven distribution of healthcare resources, which reinforces the enduring barriers to accessing healthcare services for patients who reside in less favored areas of the country.

Nevertheless, breast cancer patients have better prospects for a longer life expectancy – both in Turkey and globally – than those with some other types of cancer, thanks to its curability, especially in cases of early detection which is followed by timely and effective treatment (Çakmak et al., 2019). This underlines the importance of healthcare policies in ameliorating the quality of life and improving the treatment pathways of breast cancer patients in Turkey.

Against this backdrop, the first section of this chapter describes the changes in the healthcare system structure by comparing the financing, provision, and regulation of the Turkish healthcare system before and after the 2003 reforms. The second section will provide a background for breast cancer in the country from the late twentieth century onwards and offer insights into the treatment of breast cancer

in the Turkish healthcare system before and after the 2003 reforms. The final section will present an overview of the literature on Turkish breast cancer patients; their various needs, experiences of the illness, expectations for treatment, and problems they encounter.

3.1 Turkish Healthcare System

Healthcare system typologies exemplified in the foregoing chapter are predominantly developed based on the cases of North American and Western European countries. In this regard, Wendt's (2014) typology can be considered as an exception since it classifies 32 OECD countries, including Korea and Japan from Central Asia as well as Turkey and Israel from the Middle East and North Africa region. Wendt's (2014) comprehensive classification is based on the following indicators: the share of total health expenditure, public financing, and out-of-pocket payments, in-patient and out-patient indexes, the remuneration of general practitioners, and access regulation index (Wendt, 2014, p. 7). According to this study, Turkey and Israel form their own type of healthcare system, which is characterized by a low level of total health expenditure, the below-average capacity of in-patient and out-patient healthcare, the remuneration of general practitioners based mostly on salary, and unregulated access to medical practitioners. However, it is crucial to note that the data collected from Turkey for Wendt's (2014) study coincides with the implementation of Turkey's HTP in the early 2000s.

The HTP has significantly transformed all aspects of healthcare policy in Turkey with respect to financing, provision, and regulation since 2003. A discourse on efficiency and productivity alongside equality has been the primary notion that has guided the HTP in terms of the overall structure and organization of healthcare

services (Başol & Işık, 2015). In this respect, it appears somewhat problematic to follow the analysis of healthcare systems as suggested by Wendt (2014) in contextualizing the Turkish healthcare system as we know it today. Thus, upon providing a brief historical background, this section will focus on the current structure and major functions of the post-HTP Turkish healthcare system in terms of financing, provision, and regulation.

3.1.1 Turkish healthcare system before the 2003 reforms

Before the major structural reforms regarding the social insurance system in Turkey at the outset of the 2000s, the Turkish healthcare system exhibited substantial disparities. The most apparent disparities were related to access conditions, benefit packages, premium rates, and the quality of services amongst different public insurance funds. Besides, private funding of healthcare provision was highly limited (Bump et al., 2014). The system was composed of three institutions, each related to a different occupational group (Boratav et al., 2000), and the hierarchy amongst patients was predicated on both closeness to the state as well as employment status (Üstündağ and Yoltar, 2007). This type of social security system was detrimental to those who did not possess a social security insurance plan through formal employment, which constituted almost half of the population (Buğra and Keyder, 2006). Although the issues with exclusive coverage were partially resolved by the Green Card Scheme established in 1992, which was a means-tested, tax-funded social assistance program that granted access to inpatient services (Karadeniz, 2012), the scheme itself was very narrow in terms of benefit packages and it did not reduce the burden of out-of-pocket spending (Ağartan, 2012). Both formal and informal out-of-pocket payments were a major problem in healthcare. Tatar et al. (2007) find that

in 2002, informal payments to service providers accounted for a quarter of all out-of-pocket spending, with the majority being for outpatient care. Hence, although marketization was minimal prior to the initiation of the HTP, the “commodification of healthcare” began to pose a growing handicap for those who could not afford out-of-pocket spending and were thus denied necessary treatment (Ağartan, 2012, p. 463).

Historically, the leading agent in the delivery of healthcare services was the state. Different kinds of public hospitals were the predominant healthcare providers along with private clinics of physicians. In addition to the apparent social inequalities caused by the fragmented healthcare system, regional cleavages were also paramount in terms of the distribution of healthcare resources amongst the urban and rural areas found in the eastern and western parts of the country (Chawla, 2003). Even though the practice of purchasing healthcare services from private providers existed before the HTP, the share of the private sector in healthcare provision was considerably low (Yılmaz, 2017). Ağartan (2012, p. 462) describes the regulatory disposition in healthcare before the HTP as a system of “command-and-control”, markedly concerning the healthcare providers. While the public agents established the criteria for coverage and set the standards for premium rates and co-payments, the limited regulatory capacity of the insurance funds resulted in meager benefit packages (Ağartan, 2012). Considering that the healthcare system before the HTP intemperately counted on out-of-pocket payments and allowed for private healthcare delivery through private practices of physicians, Yılmaz (2017, p. 75) asserts that the regulatory capacity of the state was inadequate, which is indicated in its failure to surmount “the informality enmeshed into the formal healthcare system”. This was the regulatory context in which the HTP was launched.

3.1.2 Turkish healthcare system after the 2003 reforms

The goal of the HTP was to initiate a compulsory general health insurance scheme with coverage based on citizenship, which was eventually established in 2008.

Yılmaz (2017) states that the changes brought about by the HTP led not only to the unification of three public health insurance schemes as well as the Green Card scheme under the newly founded SGK but also standardized the basic benefit packages for the compulsory GSS.

The SGK became the authority in determining what is included in the basic benefit package, namely the kind, duration, and amount of diagnostic and treatment services as well as medications. It has become the single-payer that purchases healthcare services from both public and private providers for publicly insured patients at predetermined reimbursement rates. A service contract with a private provider might either cover all services provided by that hospital or only include specified specialist services and reimbursement rates are largely predicated on diagnosis-related groups with such exceptions comprising emergency services and/or oncology services, which are on a fee-for-service basis (Yılmaz, 2020).

The HTP brought about extra sources of financing the healthcare system, namely compulsory flat rate patient contributions (co-payment) for medications and all hospital visits, additional fees (co-insurance) for private hospital visits as well as optional supplementary private health insurance (Yılmaz, 2013). First, patients are thenceforth required to co-pay for medications and outpatient services in public healthcare facilities as part of their GSS plan. Those who have pre-defined acute and/or emergency conditions, as well as those who live under a certain poverty threshold, are exempt from co-payments. Turkey also implements a cap on co-insurance that patients make to private providers offering publicly funded services.

The HTP also resulted in the creation of an internal market for healthcare delivery, which incorporated PHOPS as the main actors in the provision of healthcare (Yılmaz, 2017). Co-insurance for PHOPS, which is determined by the Council of Ministers, has consequently emerged as a second new component of financing the system. This means that patients can access services offered by PHOPS as long as they are eager and able to make extra payments to top up their GSS scheme (Yılmaz, 2017). The SGK enforces an upper limit for supplementary fees that PHOPS can charge patients. Yılmaz (2017) notes that at the start of this practice, the cap was 30% of the SGK rate for the top-level PHOPS, which has stretched to almost 200% in 2013. The HTP provided an option for supplementary private health insurance to cap the compulsory GSS, which grants financial security regarding supplementary payments in private hospitals where publicly insured patients can benefit from services (Yılmaz, 2017). Lastly, yet importantly, the uptake for supplementary PHI in Turkey has shown an upward trend in the years following the reforms (Hışıl, 2020).

This new model did not cause major changes in the prevailing insurance-based financing model in Turkey because, as Yılmaz (2017) asserts, while it made no changes to the residual tax-financed element, it also mandated that all citizens make contributions to the SGK Fund irrespective of their employment status. Enduring such a financing model based on social insurance for healthcare, the state contributes to the SGK fund approximately a quarter of all premiums collected monthly, which to some extent improves the financial sustainability of the system but can still be regarded as a “recalibration” rather than a drastic deviation from the pre-reform healthcare financing model (Yılmaz, 2017, p. 87).

Ultimately, these macro-level changes executed by the HTP steadily increased the leverage of public funding in healthcare financing, and, owing to the newly established compulsory GSS, the Turkish healthcare system has been considered as having achieved UHC (Ağartan, 2020). Particularly in terms of financing, Ökem and Çakar (2015) suggest that the reforms brought about by the HTP have overcome the long-lasting issues with informal payments and thus ameliorated equity in access. Nevertheless, as Yılmaz (2020) aptly demonstrates, patient experiences of accessing treatment thus far indicate significant loopholes in the public regulation of the internal market system in healthcare delivery in the Turkish context. Therefore, the negative implications of this system and its prevailing issues in terms of equality in accessing treatment should not be understated.

The provision of healthcare has undergone major structural changes in the 2000s. The HTP led to the transformation of the MoH into a “planning and monitoring body”, which paved the way for the creation of a “quasi-market” in healthcare delivery (Yılmaz, 2017, p. 89). The new position of the MoH laid the foundations for newly emerging health enterprises operating from public hospitals and increased the role of the private actors in the provision of healthcare (Erençin and Yolcu, 2008). This meant that not only private but also public hospitals have become more autonomous in making organizational decisions and have taken more responsibility for finance and service quality (Saraçoğlu et al., 2012). The creation of the internal market for healthcare delivery was justified by the advantages of increased competitiveness and patient autonomy, at least theoretically (Yılmaz, 2020).

In this new setting, the state came to be the purchaser of services through the SGK instead of being the only provider. To summarize the key steps taken by the government, the SGK hospitals were consigned to the MoH, and public hospitals were endowed with partial administrative and financial autonomy; the private sector was enabled to build public-private partnership hospitals (namely, “city hospitals” in Turkish) on public property, collect rent from the state and provide commercial healthcare services; finally, private investors were incentivized to establish new private hospitals to be contracted with the SGK, namely PHOPS (Yılmaz, 2017).

While the number of private hospitals was increasing, private clinics that belonged to physicians, which had been a significant component of the healthcare provision prior to the reform, were excluded from the public health insurance plan (Yılmaz, 2017). In the aftermath of the HTP, the state began to purchase healthcare services from private providers on a far greater scale compared to the years predating the reform (Ağartan, 2012; Yılmaz, 2017). As a consequence, not just generally the volume of the private sector in healthcare but also particularly the share of spending to private hospitals from the SGK budget has dramatically risen since the implementation of the HTP (Sönmez 2017, pp. 35-66).

The provision of medications was also subjected to substantial changes after the HTP in that the beneficiaries of the SGK Fund became eligible for acquiring medications from privately owned pharmacies and since the Green Card users were bestowed with standardized benefit packages, they could also access medications via private pharmacies, which denoted a considerable amelioration in the most vulnerable patients’ access to healthcare in Turkey (Yılmaz, 2017).

Last but not the least, the HTP has brought Primary Healthcare Services and Family Medicine into the Turkish healthcare system. The rationale was to strengthen

primary healthcare services so as to deal with the congested public hospitals and exorbitant healthcare costs (Ergun & Ergun, 2010). However, primary care still does not have any gatekeeping role in the Turkish healthcare system. Besides, patients were emboldened to choose their family practitioners for primary healthcare services, which was concomitant with the widespread discourse regarding the importance of patient choice in healthcare (Hone et al., 2017).

On the whole, the HTP resulted in better social insurance coverage for the lowest strata of the society, which has drastically risen from 2,4 million people in 2003 to 10.2 million in 2011 (Atun et al., 2013). In line with this, the levels of healthcare system satisfaction amongst individuals from different income groups in Turkey indicate that those with lower income were more satisfied than others with higher income during and after the reform over the period of 2003–11, which refutes the general trend observed in developing countries where publicly funded healthcare services are more likely to privilege higher-income groups (Hazama, 2015).

The hybrid Turkish healthcare system after the reforms is fruitful for analyzing the regulatory environment because the HTP led to the transition from public to mixed healthcare provision at the same time preserving the insurance model of financing (Yılmaz, 2020). The regulation of this newly emerged internal market for healthcare delivery has undoubtedly been complex. One of the significant issues stems from the transformation of some private hospitals into PHOPS after their incorporation into the GSS plan in 2005 because, as Yılmaz (2020) states, it has been challenging for many patients to inform themselves about which hospitals are contracted with the SGK, which services are covered and which are not, and what are the lawfully authorized rates of co-payment and co-insurances. As a response to this widespread information asymmetry between healthcare providers and patients, the

SGK developed an online platform where patients can access necessary information (Yılmaz, 2020).

Besides, the binding agreements between the SGK and the PHOPS are designed in such a way that the latter is subjected to specific penalties in case of noncompliance (Yılmaz, 2020). To illustrate, the SGK postulates that PHOPS must post a noticeable sign showing the legally permitted fees that patients are expected to pay and that PHOPS must provide a receipt listing each service provided to the patient. A fee equivalent to five times the surcharge is imposed in the event of non-fulfillment. Nonetheless, Yılmaz (2020) rightfully denotes that the efficaciousness of these regulatory measures has yet been equivocal.

Last but not the least, the SGK outlawed charging co-insurance for several services and began to fully reimburse these services in 2010, which involves but are not limited to emergency services (ER), cancer treatments, neonatal and intensive care as well as surgical operations for congenital anomalies and certain cardiovascular diseases (Yılmaz, 2020). Yılmaz (2020) asserts that the effectiveness of this regulation has not yet been adequately assessed.

3.2 Breast cancer in the Turkish healthcare system

Meaningful cancer awareness in Turkey only dates back to the second half of the twentieth century. Until the Turkish Association for Cancer Research and Control was founded as a civil initiative in the 1950s, cancer awareness had not been promoted and the procedures regarding detection and treatment were not structured (MoH, 2011). Prior to the establishment of two oncology hospitals in Ankara in 1962, general hospitals managed cancer treatment (MoH, 2009). In 1970, the

government established a separate directorate in order to institutionalize the combat against cancer (MoH, 2009). It was not until the 1990s that Turkey became a member of the International Union against Cancer to build international partnerships regarding cancer care (MoH, 2009).

The MoH eventually launched a five-year National Cancer Control Program in 2009, which incorporated a central cancer registry, prevention, screening, early diagnosis, treatment, and palliative care (Tuncel-Oğuz, 2021). However, as Özmen (2013) postulates, Turkey still needs to seek better quality and all-inclusive cancer registration and national screening programs because it is crucial to operationalize a thorough and meticulous cancer registry for the implementation of a nationwide cancer control agenda as well as the assessment of diagnosis and treatment procedures. This is because neither prioritization nor rational decision-making could be accomplished in the formulation of national health policies, development of strategic plans, and utilization of scarce resources in the dearth of accurate data collection and statistical assessment (Özmen et al., 2019).

3.2.1 Early detection

In 2004, drawing from European Guidelines, the Cancer Control Directorate of Turkey prescribed biannual mammographic screening for women between the ages of 50 and 69 despite the fact that almost 50% of all Turkish breast cancer patients were below the age of 50 (Özkan Gürdal et al., 2021). As a result of later clinical and prospective studies, the lower limit for screening was determined as 40 years (Duman et al., 2020). Cancer screenings in Turkey are administered by Cancer Early Diagnosis Screening and Training Centers (*Kanser Erken Teşhis, Tarama ve Eğitim Merkezleri*, KETEMs), which have been free-of-charge since 2008. Currently, there

are 183 centers spread throughout the country, at least one in each city (Halk Sağlığı Genel Müdürlüğü, 2021). KETEMs are responsible for the organization and training of the health personnel alongside informing the public and raising awareness on breast cancer, providing a diagnosis in early stages by means of nationwide screening programs for identified risk groups, initiating the referral to treatment centers, and the follow-up procedures for patients diagnosed with cancer, and finally, offering additional psychological, and social support (Kebudi & Çakır, 2016).

3.2.2 Insurance coverage and access

The reforms brought by the HTP resulted in improvements regarding oncological care, albeit to a certain extent. Cancer patients were deemed exempt from making any additional payments for radiotherapy and chemotherapy services by the regulation issued in 2010, which encompassed not only public hospitals but also PHOPS (Başol & Işık, 2015). The SUT formulated by the SGK declared in 2010 that not only standard cancer treatment would be free of charge but also it would be available across the country (Official Gazette of the Republic of Turkey, 2010). The goal of this regulation was to ease cancer patients' access to standard treatment. Besides, several studies indicate that there is a positive correlation between early access to new cancer medications and survival rates for both general and specific cancer types (Lichtenberg, 2007; Sun et al., 2010; von Plessen et al., 2008). In congruence with this, the HTP reforms implemented far simpler procedures of approval and reimbursement of novel cancer drugs so that the bureaucratic formalities would be bypassed and application processes would become more transparent and cost-effective (Wilking et al., 2010).

3.2.3 Healthcare resources

Despite that the technological overhaul of public hospitals has been ongoing (Karakoyun Çelik, 2014), the latest available OECD data from Turkey demonstrates that there are 11.9 mammography machines (ranking 23rd out of 28 countries) (OECD, 2021a) and 11.2 magnetic resonance imaging (MRI) machines (ranking 24th out of 31 countries) (OECD, 2021b) available in total. This makes it clear that the resource capacity of the Turkish healthcare system in terms of screening remains insufficient since the numbers are far below the OECD average (OECD, 2021a, 2021b). Similarly, even though the opening of private radiation therapy centers has been endorsed in congruence with the overall privatization pattern in the Turkish healthcare system (Karakoyun Çelik, 2014), the latest OECD data reveals that there are only 2.8 radiotherapy equipment (ranking 28th out of 29 countries) per 1.000.000 people in Turkey (OECD, 2021c).

The low numbers and uneven distribution of radiation oncology centers throughout the country pose a great obstacle to breast cancer treatment (Kuter & Çakır, 2004). Most of the existing facilities lack appropriate technological and medical equipment and personnel (Kuter & Çakır, 2004). The insufficient number of medical and radiology oncologists and surgeons skilled in new techniques hinders the assessment of radiological results in a timely and proper manner, which may partially explain why the majority of breast cancer incidences are detected at later stages in Turkey (Özmen, 2013). The hospitals where there is the necessary equipment and experienced medical staff are located in big cities, thus compelling patients to commute across the country for better treatment opportunities (MoH, 2011).

Considering the accumulation of breast cancer patients in big and urban cities, hospitals are oftentimes at full capacity in terms of in-patient treatment. More importantly, there is a large number of patients per doctor whereas the number of oncology nurses is seemingly scarce (Aydın, 2021) despite the fact that nurses specialized in the oncology field are pivotal for palliative cancer care.

As such, palliative care has been the most incapacitated branch amongst all cancer control activities in the country (Tuncel-Oğuz, 2021) The number of palliative care experts and hospice centers is still considerably low in Turkey and there is no agenda for specific hospice care centers, community hospice teams, or home palliative care teams (Tuncel-Oğuz, 2021).

On a final note, Karakoyun Çelik (2014) stresses the income inequality between physicians caused by the new performance-based additional payment policy initiated by the MoH as part of the HTP. Coupled with the full-time work law decreed by the HTP, this new payment policy results in the transfer of several top-level medical staff to private hospitals, which raises a significant issue regarding the future of public university hospitals in Turkey where high-quality services for such complex diseases, such as cancer, have been largely provided (Karakoyun Çelik, 2014).

3.2.4 Standard oncological treatment

In Turkey, breast cancer patients often receive the standard oncological treatment, which is fully funded by social health insurance for all citizens. However, the availability and quality of these services might differ considerably from region to region (Özmen, 2018). Most of the oncology centers in the country treat patients

according to the US or European-oriented and globally recognized protocols (Kebudi & Çakır, 2016). There are many treatment options for women diagnosed with breast cancer. Standard treatments range from surgical operations to chemotherapy and radiotherapy as well as hormone therapy and biological therapy (Türkiye Meme Hastalıkları Dernekleri Federasyonu [TMHDF], 2021). Other potential treatment options are being assessed in clinical trials. The SUT provided by the SGK states what procedures and which medications are included in the standard treatment.

In most cases, the stage of the cancer is the main determining factor regarding which treatment options are available. Breast cancer patients mostly receive more than one treatment simultaneously or one after the other. The treatment of breast cancer can either be local treatment or systemic therapy. The goal of the former is to eliminate or destroy cancer cells alongside controlling the spread of the illness to other organs by means of surgery or radiotherapy. The latter, namely, chemotherapy, hormone therapy, and biological therapy, aims to infiltrate into the blood to control and eventually destroy cancer in the whole body. While systemic therapy may be used to shrink the tumor before any local intervention, vice versa is also possible to prevent cancer from recurring. Research with a follow-up period of more than 20 years indicates considerable changes in the treatment of early-stage breast cancer as breast-conserving surgery (BCS) has largely replaced radical mastectomy due to equal survival rates (Akyolcu et al., 2019).

Both standard and novel chemotherapeutics, as well as a number of drugs used for targeted therapies, are available on the market for healthcare in Turkey (Koçkaya et al., 2011). Increasingly, some of the targeted therapies are also funded by the government by means of applications for off-labeled drugs, which are not included in the standard treatment (Kebudi & Çakır, 2016). The majority of off-label

prescriptions have been recorded in palliative care patients (Koçkaya et al., 2011) and while some of these drugs are known for clinical benefits, others constitute the standard of care for specific cancer types (Levêque, 2008). In 2009, off-labeled oncology drugs imported to Turkey accounted for 14% of the overall cost of cancer medications provided by the SGK (Koçkaya et al., 2011). Koçkaya et al. (2011, p. 55) indicate that breast cancer had the greatest off-label application in the years 2008, 2009 and the first half of 2010 (1597, 2409, and 3241 respectively).

Ursavaş and Karayurt (2017) succinctly put that it is by no means sufficient for patients to receive medical treatment, be it surgery, chemotherapy, radiotherapy, or hormone therapy, to overcome breast cancer. This is because the illness largely impacts patients' biopsychosocial wellbeing, therefore, the provision and upkeep of mental support for breast cancer patients both during and after the medical treatment procedures should be included amongst the major criteria for the therapeutic process (Ursavaş & Karayurt, 2017). However, only a limited number of cancer treatment facilities employ psychologists and psychiatrists; in most others, a psychological consultation is sought whenever deemed necessary from the corresponding department, if there is any (Kebudi & Çakır, 2021). There is also a lack of other important specialists such as social workers and art therapists in oncology centers, which renders the physicians and nurses to cover these roles on top of their primary responsibilities (Kebudi & Çakır, 2021). Considering the inextricable relationship between intensive stress and breast cancer (Özdemir et al., 2009), the current situation reveals that institutionalized mental support offered to cancer patients remains insufficient in Turkey.

3.2.5 Alternative treatment approaches

Although this thesis will not focus on alternative treatment methods, it should be mentioned that Turkish cancer patients use a noteworthy amount of non-proven treatment methods in their pursuit of cure despite the fact that there is yet little research on the use of these methods related to patient characteristics and disease features (Kebudi & Çakır, 2016). A study performed on cancer patients at Akdeniz University Medical School Hospital established that 50% of the participants have primarily appealed to medicinal herbs, the most frequently used plant being stinging nettle (Samur et al., 2001). The majority of patients reported that they have tried more than one item, including but not limited to honey, pollens, molasses, garlic, olive oil, rosehips, parsley, and spice mixtures (Samur et al., 2001). Another intriguing finding of Samur et al.'s (2001) study is that the most common supplemental therapies reported in western nations, such as prayer, psychotherapy, physiotherapy, meditation, and nutrition counseling, have not been used extensively by Turkish breast cancer patients except for the those who resided in big urban cities. Can et al. (2012) assert that while several alternative treatment approaches employed by cancer patients are deemed safe, certain misconceptions related to the benefits of exercising could be detrimental for patients with spinal metastasis. It is thus crucial to raise awareness regarding non-proven treatment methods in breast cancer treatment.

3.3 Existing studies on Turkish breast cancer patients

The literature on the experiences of Turkish breast cancer patients can be viewed as dispersed since researchers in this field have chosen to employ diverse conceptual frameworks. One of the most prominent of these frameworks is the quality of life (or

satisfaction with life) assessments of breast cancer patients. Quality of life (QoL) involves the psychosocial, physical, financial, and emotional aftereffects of healthcare as discerned by the patient (Öğce et al., 2007). The QoL of breast cancer patients is influenced by several factors, namely age, civil status, employment position, level of earnings, profession as well as disease phase, chemotherapy, chemotherapy procedures, and kind of breast surgery (Akın et al., 2008). In congruence with the general trends in the international literature, Akın et al. (2008) indicate that the QoL is more adversely affected in younger Turkish breast cancer patients. Therefore, it can be deduced from these findings that younger patients might need more physical, psychosocial, and emotional support.

Marital status is another determinant of the QoL of patients, however, the findings related to this indicator have been inconsistent. While Güner et al. (2006) suggest a better QoL in married women with breast cancer, Akın et al. (2008) report that the QoL of married women is more negatively affected by the disease. Similarly, Avcı and Kumcağız (2011) show that women reported worsened relationships with their husbands following breast cancer surgery. Two studies with Turkish breast cancer patients demonstrate that a low level of earnings has negatively influenced the QoL as well (Güner et al., 2006; Öğce et al., 2007). In terms of employment status, Öğce et al. (2007) state that employed breast cancer patients experience less psychological stress compared to the unemployed. Besides, Öğce et al. (2007) highlight that the QoL and all its broader dimensions deteriorate as cancer progresses to later stages. Last but not least, another QoL study performed in Istanbul, Turkey indicates that the extent of psychological symptom distress in Turkish breast cancer patients before treatment (chemotherapy) is greater than the level of distress caused by physical symptoms (Can et al., 2004).

Seven et al.'s (2021) recent study explores the unprecedented effects of the Covid-19 pandemic on the QoL of breast cancer patients. They find that akin to all types of cancer, breast cancer patients have been facing drawbacks that stem from the restricted availability of healthcare resources due to several preventive measures taken to reduce the exposure of the virus and the risk of infection for patients with chronic illnesses. Seven et al. (2021) argue that there are novel challenges for breast cancer patients during the pandemic, which renders alternative healthcare provision to be paramount both in terms of the physical and mental wellbeing of patients. For instance, the circumstances created by the pandemic have led to weight gain due to the absence of physical activity, which brought about an increase in such symptoms as pain and chronic fatigue, even lymphedema (Seven et al., 2021). In terms of the psychological impact of the pandemic, increased prevalence of depression and anxiety appear to negatively influence the QoL of breast cancer patients (Seven et al., 2021). In view of these findings, Seven et al. (2021) conclude that it is crucial for oncology personnel to work in communication and cooperation within a multidisciplinary oncology department for them to demonstrate leadership in managing the pandemic in oncology settings, thus addressing the needs of cancer patients during such a grave public health emergency.

Although many researchers have predominantly concentrated on the QoL scheme, research on functional status amongst breast cancer patients diverts from the QoL to an extent and provides a “multidimensional analysis” (Özkan & Öğce, 2008, p. 601) which is built on family, household, social surroundings, community, self-care, and professional life and which indicates a patient's perception of how an illness and its therapeutic interventions affect one's day-to-day functioning. As such, Özkan and Öğce (2008) argue that just as QoL assessments, the evaluation of

functional status should be formulated as an essential criterion for cancer treatment since it can distinctively reveal knowledge and insight into patients' needs and aspirations. Özkan and Ögce's (2008) study examines the relationship between social support and functional status amongst women with breast cancer who undergo some kind of treatment. Their findings reveal the importance of the design and implementation of social support networks to enhance the functional status of breast cancer patients. These results are consistent with Filazoglu and Griva's (2008) study, which finds a positive correlation between social support and health-related QoL in Turkish women with breast cancer.

The self-assessed needs of patients appear to be another increasingly significant conceptual framework (Erci & Karabulut, 2007). Studies on patient experiences of illness and treatment have gained prominence and increased in number over the last decades. Several studies that focus on breast cancer patients' self-evaluated needs demonstrate that women seek a high level and various forms of support related to breast cancer (Cebeci et al., 2012; Çömez & Karayurt, 2015; Erci & Karabulut, 2007; Fındık, 2017). In addition, breast cancer patients commonly express their informational needs with regards to a range of aspects related to the disease and its treatment (Cebeci et al., 2012; Çömez & Karayurt, 2015; Erci & Karabulut, 2007; Fındık, 2017). Besides, breast cancer patients often voice and strongly feel psychosocial needs and expectations associated with healthcare providers, information, and support networks (Erci & Karabulut, 2007).

Erci and Karabulut's (2007) study conducted in Erzurum, Turkey explores the effects of breast cancer on women's requests for various types of support. The main objective of this research is to categorize the self-reported needs of breast cancer patients, which might serve as the foundation for a standardized scale of

needs in the assessment of healthcare services. Erci and Karabulut (2007, p. 141) find that the “family and friends” support kind is the highest reported support need (79%) of the participants, which is followed by “after care” (78.3%) and “treatment” (62.9%). Statistically significant differences by age were detected since the youngest age group of 20–45 years manifested higher levels of neediness compared to the two older groups (46-53 and 54+) in all categories, especially in terms of femininity and body image. The needs related to the notion of femininity and the perceptions of body image were articulated heartily by the youngest age group in terms of adapting to their changing bodily features and having this compromised by their partners (Erci & Karabulut, 2007).

The salient impact of a breast cancer diagnosis on patients’ life can appropriately be explored by means of a qualitative approach, which lends itself well to comprehend and decipher emotions, perceptions, dealings, and comportments of individuals so as to stipulate the particular conversions that come into play (Streubert & Carpenter, 2011). In the literature, there is an increasing number of qualitative studies on Turkish breast cancer patients (Cebeci et al., 2010; Küçükkaya, 2010; Şengün-İnan et al., 2014). These studies substantiate the common themes noted by the bulk of the participants, especially regarding changes in physical appearance and female sexuality.

For instance, Cebeci et al. (2010) make a significant contribution to the literature on breast cancer patient experiences as it is the first qualitative study that examines the experiences of Turkish women with breast cancer at all stages and provides preliminary knowledge on the subject. Concerning the experiences of women living with breast cancer, three main themes emerge from Cebeci et al.’s (2010) findings: needs, living with losses, and changes. While the multiplicity of

needs includes support from relatives, spiritual needs (pray and worship), and the need to obtain information, the losses are largely related to treatment (breast and hair loss). The third theme, changes, involves transformations in patients' daily life and activities, their self-perception, and the way they value their health as well as their enthusiasm for life. The findings of this research provide important insights into the cultural sensitivity of a breast cancer diagnosis as well. For instance, all participants admitted that they consider losing their breast as a traumatic experience and a "loss of womanhood" (p. 411), as the breast symbolizes femininity and sexuality in many societies. Turkish women declared that the loss of hair did not impact their wellbeing as much as the loss of a breast, which runs counter to the findings of Doumit et al. (2010) that the most detrimental and dispiriting experience was hair loss amongst Lebanese patients.

Şengün-İnan et al. (2014) highlight that research on breast cancer patient experiences at the stage of diagnosis has generally been limited and this is reflected in the literature on Turkish women with breast cancer as well. They argue that it is important to identify breast cancer patient experiences throughout the diagnosis phase because it enables for early detection of future difficulties alongside providing assistance to the patient. The findings of their qualitative study with 9 breast cancer patients comprise four themes: confronting the diagnosis, uncertainty, avoidance, and holding onto life. Patients revealed that they experienced melodramatic episodes and severe mood swings when they first confronted the diagnosis, then felt insecure regarding the progression of the disease, treatment options, treatment outcomes as well as social relationships (Şengün-İnan et al., 2014). As such, patients isolated themselves from their surroundings and avoided manifesting unpleasant feelings to

others but at the same time referred to religion, positive life attitudes, and social support for holding onto life (Şengün-İnan et al., 2014).

The literature, especially the psycho-oncology field, is dominated by studies on the negative outcomes of breast cancer on patients. More recently, however, this focus has shifted due to positive changes reported by patients after the diagnosis of breast cancer (Manne et al., 2004). International research put forward posttraumatic growth amongst breast cancer patients, however, there is still not enough research conducted on positive changes experienced by Turkish breast cancer patients (Karanci & Erkam, 2007; Küçükkaya, 2010) even though the prevalence of breast cancer has soared in Turkey in compliance with the global trends. The findings of Küçükkaya (2010) indicate that 50% of the patients who had early detected breast cancer encountered positive changes in the aftermath of their diagnosis. The changes reported by patients were clustered into four main themes, namely empowerment, changes in perception of the self, changes in interpersonal relations and, finally, greater appreciation of life (Küçükkaya, 2010). For instance, patients may consider people around themselves to be more worthy, become more compassionate, sagacious, and perceptive in complying with limitations and weaknesses in life, and appreciate their time alive more so than usual.

In addition, Küçükkaya (2010) finds a correlation between the educational level of the patients and posttraumatic growth following the disease. She posits that because Turkish women who have poor educational backgrounds are more prone to have poorer socioeconomic positions in society, they might face problems in affording cancer treatment. In other words, especially female patients who are not economically self-reliant might feel discomposure about being an encumber to their family because of the illness and therefore do not experience any positive changes

(Küçükkaya, 2010). Nonetheless, it is important to note that the broader literature still demonstrates controversial findings on this correlation. Overall, 70% of participants reported experiences of high social support and 50% regarded the illness as an occasion for empowerment and a positive transformation in the way they perceive, value, and respect themselves (Küçükkaya, 2010, p. 168).

Breast cancer treatment sometimes includes a surgical operation. Since the 1990s, a large amount of research has corroborated that BCS along with radiotherapy corresponds to mastectomy (removal of the breast) in terms of oncological health consequences (Martin et al., 2006). BCS is seen to sort the problems with body dysmorphia and accompanying sexual and mental problems (Fallowfield et al. 1990). Turkey has a BCS rate of less than 50% (Özmen, 2018). Yüksel et al. (2018) explore what factors are prominent in the choice of operation for patients at the early stages of breast cancer, what are the informational sources enjoyed by patients about the treatment of the disease, and the extent to which that information is taken into account by patients. Yüksel et al. (2018) assert that in Turkey, 35% of surgeons allow their patients to decide between BCS and mastectomy upon providing the necessary information but the majority of Turkish surgeons are prone to control their patients' choices in such a way that they find most suitable.

Another important factor in the decision-making process is the absence of self-esteem due to poor social standing as patients may be reluctant to voice their thoughts and concerns with regards to the alternative surgical treatments (Yüksel et al., 2018). Besides, many patients may not be able to determine the advantages and disadvantages of different surgical techniques (Yüksel et al., 2018). Age also appears to be a significant factor in choosing between surgical techniques since the age of the patient is the by-product of body image problems and the desire to give birth and

breastfeed. Even though younger patients generally prefer BCS and are more inclined to pursue a second opinion, Yüksel et al.'s (2018) findings state that this rate was only 8% in their study. They argue that an increased preference for mastectomy is partly due to more aggressive biological features amongst young breast cancer patients, growing knowledge of family history, and more prevalent access to genetic screening.

Furthermore, it is important to highlight that most patients who participated in Yüksel et al.'s (2018) research reported that they were puzzled by online searches on breast cancer throughout the decision-making process rather than being helped and guided. This led Yüksel et al. (2018) to conduct an online search in Turkish on breast cancer and treatment alternatives where they discovered that the majority of websites were created by non-experts and provided inaccurate information on the subject. Thus, the aspect of regulating and auditing health information in these platforms once again appears to be tremendously important for preventing information pollution, which is hazardous for patients' decision-making about their treatment pathways.

Integrated healthcare services are expected to improve the quality of healthcare and clinical pathways can be viewed as extensive expositions of healthcare services (Taştan et al., 2012). In this respect, clinical pathways can be viewed as tools that present an integrated approach to patient evaluation, treatment planning, and performance. In line with this, the implementation of clinical pathways for patients is another emerging research field in the Turkish context. Taştan et al. (2012) unveil that the implementation of a clinical pathway for breast cancer patients by the hospital where they undergo breast surgery provides several advantages such as improved patient satisfaction, lessened anxiety levels, and generally ameliorated

life standards (albeit not influence the duration of hospitalization). Taştan et al. (2012) argue that diagnostic procedures and surgical interventions coupled with the psychosocial challenges that may arise in the aftermath of the operation and/or during post-operative medical treatments can be traumatic for a patient and her family. Consequently, clinical pathways for breast cancer patients entail a “multidisciplinary, team-based approach and continuity in care” (Taştan et al., 2012, p. 368).

The need for integrated patient pathways is materialized the most when it comes to long queues and waiting lists over the periods of diagnosis and treatment of breast cancer, as hospitals are essential components of healthcare systems (Camgöz-Akdağ & Cantürk, 2017). This is partly due to unbalance between the ever-growing demand and inadequate healthcare resources. In line with this, Camgöz-Akdağ and Cantürk (2017) examine the ways in which breast cancer patient pathways could be ameliorated according to the European Society of Breast Cancer Specialists Standards and Guidelines. In this study conducted in a Training and Research University Hospital in Kocaeli, Turkey, Camgöz-Akdağ and Cantürk (2017) outline the present situation of the Turkish healthcare system in which they identify the gridlocks and the activities that serve no useful purpose. By means of the Value Stream Mapping tool, Camgöz-Akdağ and Cantürk (2017) present the steps taken by breast cancer patients to be appropriately diagnosed. They identify that a superfluous number of tests and waiting times for their results, patients’ roaming between various units for registration and treatment as well as the insufficient training for nurses, navigators, and surgeons were the primary issues.

To illustrate some of the most apparent problems, the hospital system did not obtain systematic registration data on the pathway of patients (Camgöz-Akdağ &

Cantürk, 2017). The staff at the reception were not informed about the availability of the mammography machine, which caused them to postpone patient appointments in rush hours even though the machinery was available at that time (Camgöz-Akdağ & Cantürk, 2017). In other words, there was no effective peak-hour management as patients always waited for much longer than anticipated due to chronic delays. Patients had five minutes each for their mammography appointments, which almost always takes at least 15 minutes because patients have to change clothes in the scanning area due to the absence of private dressing places (Camgöz-Akdağ & Cantürk, 2017).

3.4 Conclusion

This chapter demonstrated that breast cancer has been a remarkably prevalent chronic health problem especially in the lives of Turkish women. The backbone of the post-reform Turkish healthcare system is the single-payer system executed by the SGK and the internal market for the provision of healthcare. Since 2010, standard cancer treatment has been included in the list of services that are exempt from the additional charge, meaning that standard cancer treatment is deemed free for all citizens at the point of service in both public and private providers, thus aiming to facilitate access to treatment, at least in financial terms. Even though cancer patients have a statutory right to access oncological surgery, chemotherapy, and radiotherapy services even in private healthcare providers, to what extent this has been put into practice is still largely unknown.

Both qualitative and quantitative studies on Turkish breast cancer patients that are reviewed in the final section of this chapter provided valuable insights into the experiences of Turkish breast cancer patients with the illness; their quality of life,

functional status, self-assessed needs, and expectations for social support. However, the literature still demonstrates a dearth of research on how the healthcare system itself shapes patients' treatment pathways, which this thesis endeavors to contribute by examining breast cancer patients' experiences and perceptions in accessing treatment in PHOPS.

CHAPTER 4

A QUALITATIVE ANALYSIS OF BREAST CANCER PATIENT PATHWAYS TO DIAGNOSIS AND TREATMENT IN TURKEY

4.1 Introduction

This chapter explores the pathways through which breast cancer patients access treatment in PHOPS in the context of Turkey, a country that has achieved UHC after the unification of different health insurance schemes under the compulsory GSS and the creation of an internal market for healthcare provision by establishing the PPS. By delving into breast cancer patients' experiences and perceptions of accessing treatment, this chapter examines how breast cancer patients navigate the healthcare system, whether their health insurance status shapes their diagnosis and treatment pathways, and how the internal market functions for breast cancer patients. It then considers the implications of these pathways in terms of patients' access to quality medical care.

This chapter is based on a thematic analysis of 12 semi-structured in-depth interviews conducted both face-to-face and online with female breast cancer patients who have recently used services and/or are currently under treatment in PHOPS in Istanbul, Turkey. While 6 of the interviewees had both GSS and PHI, the remaining 6 relied only on GSS for their treatment. The interviews (conducted in Turkish) were transcribed verbatim and analyzed. The original text of the selected quotations, which were translated into English by the researcher, can be found in Appendix F.

The identities and personal information of the participants were protected throughout this chapter. They were assigned numbers and identified as "P(number)" with their insurance status listed next to it. The names of healthcare providers

mentioned by the participants were also anonymized at all points. They were referred to by randomized letters and labeled as Public, Private, or PHOPS according to their contract status with the SGK.

This research has focused on how the healthcare system shapes patient pathways. But still, who these patients are in terms of their personal characteristics such as their age, familial responsibilities and work commitments (if any) also have an impact on these pathways. The people I interviewed were women of all ages; four of them were below 40 and 8 of them were above 40. The youngest was 26 and the oldest was 62. Except for one patient who lived alone, all of them lived with their families. Some had children and grandchildren. Working was common among my interviewees, with 8 of them working full time at the time of diagnosis, 4 of whom were retired. The women I interviewed came from different socio-economic backgrounds. When I asked about the income group they belonged to, most (7 participants) stated that they saw themselves as middle class. Three of the remainder declared themselves to be in the upper-middle-income group and the other two in the lower-middle-income group. Since no scale related to the income group was presented to the participants, their self-declared income group data were not included in the table.

This chapter presents a thematic exploratory analysis of these interviews. I found two major breast cancer patient pathways; these were differentiated primarily by the insurance status of patients. Those who had both GSS and PHI often experienced easy access to timely and effective treatment (insured patient pathway), but those who relied only on GSS experience challenges to access (underinsured patient pathway).

My analysis revealed that these pathways were determined by a combination of two interrelated factors: the projected cost of cancer treatment and barriers to accessing integrated medical care. I elaborate on these factors later in the chapter with reference to informal payments, information asymmetry, and timeliness of the information. I also considered the management and sustainability of cancer treatment and the subjective meaning attributed to it. Finally, the common obstacles that were found in both insured and underinsured treatment pathways are highlighted.

For the most part, having a conversation with breast cancer patients about their experiences of accessing treatment was not an easy task. Although the questions I directed to the participants were not focused on their experiences with the disease itself, but on their experience of diagnosis and treatment in the current healthcare system, their answers were most of the time composed of narratives in which these two were intertwined. Many patients amply talked about the psychological and physical challenges that breast cancer posed to their womanhood that sets it apart from other health issues. These interactions with patients at times led me to sympathize with patients as the researcher and there were moments when their narratives triggered emotions that I had difficulty overcoming.

Notwithstanding that the patients whom I interviewed had diverse socio-economic backgrounds, their willingness to pay was similarly very high when it came to cancer. Only 2 out of 12 participants knew that standard cancer treatment was provided free of charge as part of their GSS benefits packages. The others have either heard it from me for the first time or had learned about it but did not believe it existed. I had formulated the relevant question assuming that if patients knew that standard cancer treatment is delivered free of charge. However, when it turned out that this was not the case, I felt uneasy as a researcher. Many participants had already

paid excessive prices for breast cancer treatment, it was challenging to explain that the same treatment was available completely free and that they had certain rights and entitlements in this regard. They listened to me completely bewildered and mostly displeased.

To put it another way, the findings here corroborate Yilmaz's (2020) generalist findings on the functioning of the internal market that the current healthcare system has exacerbated the already existing information asymmetry between patients and healthcare providers, as patients must absorb and garner complex background knowledge in order to they navigate the system properly. The interviews also signaled that the PHOPS enjoy certain means of circumventing the rules and regulations by registering patients in the way that suits their financial interest the most (as either GSS holders or PHI holders). This loophole in the law has permitted the PHOPS to employ certain strategies to charge informal fees for services that should be provided free for all citizens covered by GSS, which has previously been characterized in the literature as hospitals' endeavor to "game the system" (Yılmaz, 2020, p. 15). This has an influence on the variation of breast cancer patients' treatment pathways. It is also important in understanding and contextualizing the positions of patients and providers in the Turkish healthcare system.

4.2 Breast cancer patients' treatment pathways

To illustrate breast cancer patients' pathways, I have chosen to examine how they navigate the healthcare system during the stages of diagnosis and treatment. Breast cancer patients in this study accessed treatment through two distinct patient pathways, which I describe below. The questions I asked to learn about their

experiences of accessing breast cancer treatment and diagnosis are presented in Appendix A. The insurance status of patients appeared as the main determinant of breast cancer patient pathways. Those with PHI in addition to GSS generally expressed effortless and manageable access experiences; those who relied only on GSS for accessing healthcare encountered several complications, which at times impeded their ability to access timely and effective treatment. In the existing literature on patient pathways, patients who still have to make out-of-pocket payments to access treatment despite holding insurance are once acknowledged as “underinsured” (Schoen et al., 2011). Hence, by reference to this literature, this study refers to the former group’s experiences as “insured patient pathways” and experiences of the latter’s as “underinsured patient pathways”.

4.2.1 Insured patient pathways

The vast majority of patients who followed an insured patient pathway had PHI alongside GSS, which largely allowed them to bypass the financial burden of cancer treatment in PHOPS and access integrated medical care. In particular, for the stage of diagnosis, patients who had PHI were overall more aware of the importance of annual check-ups for the early detection of breast cancer, especially mammography and ultrasound screenings on a regular basis. This partly stems from the fact that PHI schemes oftentimes grant patients with free-of-charge annual check-ups in private healthcare facilities. For instance, when explaining how she was diagnosed, Patient 4 stated:

I went to X (a private outpatient clinic). Why do I go to X? It’s a screening center where I’ve had my routine check-ups done for about 25 years. Why am I getting it done over there? I purchased private health insurance for myself in the 90s, and I always paid it regularly. It offers women mammography and ultrasound for free as a right once a year.
Patient 4-GSS and PHI (Appendix F, 1)

As this example shows, when breast cancer patients were provided with the means to access healthcare services for a timely diagnosis, they mostly used these services as 4 out of 6 patients in this study who had PHI received their diagnosis thanks to these regular annual check-ups.

While sharing their experiences regarding the diagnosis stage, some patients with PHI were not diagnosed during regular controls but resorted to a private healthcare facility for further examination of certain symptoms. For instance, a patient who incidentally noticed a mass in her breast accounted for her diagnosis as follows:

I noticed a mass in my left breast by chance, because it's an area close to the armpit, the skin is thinner, so I came across it by chance on that side. I went to a doctor in hospital K (PHOPS), I was examined by a surgeon there, he was a breast surgeon, a young doctor. He said it might not be anything serious, but we still needed to do an ultrasound and a biopsy, just to see more clearly, of course. I had the ultrasound done, but I had to go back and forth every week, I mean, COVID was in an incredible situation, hospitals and intensive care units were overflowing in April last year. Think about it, so I was a little afraid of things, I was afraid of going by myself and delayed the biopsy a bit [...] It seemed to me that it had grown a bit when I checked it again with my hand. Another ultrasound and then a biopsy because it had been 4 months since the ultrasound. Let me put it this way, I'm really lucky, I came across a very good interventional radiologist, he was a professor at K hospital. Miraculously, he found, captured, and removed a tiny cell, that is, something microscopic, such a tissue that a very small, newly formed cancer cell had spread around it. It was a great chance for me, the biopsy is really important here, the competence of the doctor who performed the biopsy is very important. It takes skill to catch it, really because my mass was less than an inch, so this was great luck for me, it was diagnosed very early actually.

Patient 3-GSS and PHI (Appendix F, 2)

As it is denoted in the above quotation, perceived medical staff competence appeared as another determinant when it came to choosing a private hospital for a potential breast cancer diagnosis.

Amongst the patients with PHI who perceived and experienced the stage of breast cancer diagnosis in the PHOPS, examples of whom are quoted above, there was only one exception to the common experiences. Patient 9 was only able to benefit from PHI through a group policy provided by her employer a few months after she felt the mass in her breast. That is to say, when she was informally diagnosed with breast cancer by the acquainted doctor, she could only rely on GSS. Patient 9 revealed the following regarding the diagnosis stage:

When I first learned about it [the illness], of course, everyone around me started recommending doctors, it was a chaotic process. Everyone was like, 'Go for this one for sure!'. At that time, a breast surgeon at Hospital Q (Private) was recommended to me. At first, I only had SGK, I was going to have private insurance in January 2021, so the November-December 2020 period had been difficult for us financially. I had biopsies, ultrasound, and mammograms one after another. I had some of them done at affordable private hospitals, for others I got an appointment from the public hospitals. Then, they didn't like the screenings, they didn't find them good at all, I had to have them done again in a better place.
Patient 9-GSS and PHI (Appendix F, 4)

As it is indicated in the above quotation, Patient 9 had to shuttle between various healthcare facilities for different procedures right before she started her treatment due to financial concerns. She also elucidated the details of her diagnosis and further examinations as the following:

The doctor at Hospital Q (Private) was taking care of us in a medical and screening center called M (PHOPS). She examined me there for the diagnosis. I am still paying the debts of my illness, let me say that the loans we took from those times continue, credit cards, so it is not over. Even though she was a close family acquaintance and we were not charged any unnecessary fees, – that we are sure about –, I gave 3.500 liras for a biopsy. It was done to me 3 times. She even searched where we could get positron emission tomography (PET) done for free, what and how we could manage all these things. If we had also fallen into the hands of those robbers, I would probably be fully broke right now. It is not possible to have a screening at Q anyway, a single screening costs around 10-15 thousand liras. We had a few of them done through SGK in M, and they sent us to a place called Hospital G (PHOPS), where we did not pay any money for a PET scan. SGK paid for it and we paid for the biopsies. Of course, there was the doctor's examination, an examination was almost 600 liras.

Patient 9-GSS and PHI (Appendix F, 3)

As this quotation demonstrates, once PHI is not at stake, the issues related to cost immediately rise to the surface with respect to patients' ability to access a timely and effective diagnosis, as it indicates how patients with PHI cope with high costs when they use their GSS, thus receiving fragmented medical care.

The vast majority of breast cancer patients who used their PHI instead of GSS revealed problem-free experiences of accessing treatment. Many received standard cancer treatment, which incorporated breast surgery, chemotherapy, and radiotherapy. For example, when I asked Patient 3 about what kind of treatment plan was offered to her, she illustrated the process as the following:

It was at that moment surgery plus radiotherapy. Anyway, I had my surgery, it was a very good surgery, I was very satisfied. It was breast-conserving surgery, only the mass was removed. It was a good thing, I was very comfortable, I stayed in the hospital for one night, I didn't pay any money, my private health insurance covered it at Hospital B (PHOPS). I had my surgery, fortunately, it was over but then the pathology came out like this. After the pathology, my surgeon said, 'We are faced with a mass with high aggression and grade 3, we will need to do chemotherapy for protection'. He made me see an oncologist at that stage. Then I met with an oncologist at B, Dr. XX, she was a very caring and a good doctor, bless her soul. She told me everything, she was never like... She was realistic, I mean. I didn't expect chemotherapy but I had it, it was 4 sessions. I received it at B too. It was in very good condition. I had no problems whatsoever, very sterile, clean, attentive. Doctors were like that too, there were psychologists, they came and visited every time, the dietitian came several times, gave information about nutrition during chemotherapy, the clinical psychologist was visiting periodically.

Patient 3-GSS and PHI (Appendix F, 5)

As it is reflected by the aforementioned example, several patients stated that they mainly relied on their PHI to afford treatment in PHOPS despite the fact that standard cancer treatment has been covered universally and fully funded by the SGK in PHOPS as well. Many specifically stated at some point in the interview that they

were registered as PHI holders rather than GSS holders at the hospital's system without having been offered to choose in the first place.

There was only one exception to this trend, as one of the PHI holders declared that she had chemotherapy and radiotherapy free of charge through her GSS in a PHOPS by the guidance of her PHI agent. She revealed her treatment experience as follows:

Even though I was in a private hospital, I took my chemotherapy drugs through the SGK in order to decrease the burden of my PHI with the guidance of my private insurance agent. There were a few contracted pharmacies in district O, they prepared my chemotherapy drugs and delivered them to my house. I then delivered them to hospital A, this is how I had chemo. For radiotherapy, the radiotherapy doctor in hospital A was a doctor contracted with the SGK, so my PHI did not cover that either. I had all these procedures done by taking advantage of the SGK at A. They said that from then on, I could get my pills through the SGK with the direction of the hospital by making a report from a contracted doctor at A. With that report, I can take my medicines for 3 months from primary healthcare centers. Nowadays, you don't even need to go there during the pandemic period, since it falls into the system of pharmacies, they see it and give it to you when the time comes. In this sense, I haven't had any problems.
Patient 5-GSS and PHI (Appendix F, 6)

As it is indicated in the quotation above, Patient 5 has not only accessed treatment without major problems but also received a substantial part of her treatment free-of-charge, including medication, only through GSS. On the other hand, it is important to note that based on the patient's narrative, it is implicit that the patient perceives GSS as a complement to PHI or as a tool used to alleviate the burden of PHI, thus considering it as a secondary means to enjoy healthcare. While other patients (PHI holders) already think that GSS would by no means cover their treatment in private hospitals, Patient 5 strategically uses GSS to finance her treatment.

The patients in this study who followed an insured patient pathway mostly received their medical treatment in an integrated way at the hospital to which they had initially referred. However, one patient stated that she had her surgery and

chemotherapy sessions in a private hospital through her employment-based PHI, but when it came to radiotherapy, she explained:

Because radiotherapy was to be taken every day and the workplace was causing troubles with absences, I started looking for a hospital that I could go to during my lunch breaks. There was hospital E (PHOPS) where I could go on my lunch break and return to work in an hour. They recommended a radiologist there and we visited them. They proposed either 32 or 34 sessions, 5 days a week, no weekends. I used to rush to the hospital by taking the subway every lunch break and going back to work from there. At first, I went to the desk and told them that my PHI has limits. After all, chemotherapy was very expensive at A (Private), which was taken from my PHI. I asked how much the treatment would cost. You know, 30 sessions could cost 20 thousand liras, 30 thousand or so... I demanded the price and they said, 'It's okay, SGK pays some of it anyway, we get the rest from your PHI.' There was nothing mentioned at that time as to how much SGK pays or PHI covers, I couldn't find out the price. They said that they would inform me at the end, but I shouldn't worry because I could benefit from either of them anyway, which would be enough for the treatment. All good, signatures were taken. Then I got the last radiotherapy. The lady at the counter said, not knowing what to do with herself, 'Can I just have you for a moment?' Holding some papers in her hand, she said that they'd gotten the provision and my share was 32,800 liras. At that moment, I turned red, my blood pressure went up. 'How much?!' I asked. You know, she might have been saying the part that the insurance covered... She repeated that my share was 32,800 liras. I asked if they were kidding me. "How much was it in total that those 32 thousand 800 liras fell on me?" I asked. They said that my PHI limit was 15 thousand liras, SGK paid 5 or 6 thousand liras, not to lie, so the remaining 32 fell on me! 60 thousand liras or so in total. I don't have such money!

Patient 9-GSS and PHI (Appendix F, 7)

As the above quotation shows, Patient 9 was faced with cost-related obstacles despite having both GSS and PHI. Because her PHI limits were exceeded, the hospital requested her to pay the remaining cost of the radiotherapy out of pocket, which is supposed to be fully covered by GSS in the first place. Thus, this narrative also stands as a vivid example of how the PHOPS might employ certain maneuvering strategies in terms of how they register patients, which enables them to request informal out-of-pocket payments from patients. At the same time, this shows that the smoothness of these insured patient pathways has its limits, which depend on the limits of their insurance policy.

In a nutshell, the most striking aspect of this analysis was that breast cancer patients with PHI did not know that cancer treatment is fully funded by GSS. The analysis of their access experiences shows that as long as treatment costs were resolved by PHI schemes, patients conveniently accessed integrated medical treatment in the PHOPS and that they were generally satisfied with the treatment they received.

4.2.2 Underinsured patient pathways

Patient pathways for those who only rely on GSS were overall precarious, especially during the treatment stage. Patient narratives regarding the diagnosis stage reveal that based on the current regulations set by the MoH, relatively younger breast cancer patients are not eligible for having a free annual check-up or a mammography screening through GSS. Even though the MoH's cancer screening programs exist, they target 40+, which not only gives a false signal for young patients but also poses a significant barrier against a timely diagnosis for young patients. The following narratives adequately illustrate this, as Patient 1 states:

While I was self-examining in the bathroom, I noticed a mass in my breast, but I thought it would not be cancer because I don't have anyone who had it in my family and also because I know that mammography isn't done under the age of 40. So, I thought that people under the age of 40 don't usually have cancer and didn't do anything about this issue for a period of 6 to 7 months. Of course, I didn't go to the doctor because I was afraid that something bad would happen, but this age limit for mammography really affected my decision at this point. Later, when I found an equally large mass in my armpit, I was very scared and went to the doctor.
Patient 1-GSS (Appendix F, 8)

Patient 1 states here that although she felt a mass in her body, she did not think that she would have cancer because mammography for women under the age of 40 is not covered by GSS, which resulted in a late diagnosis with a significant delay.

Another young patient who is only 28 years old expresses the difficulties she has faced during the diagnosis stage as follows:

In November, I noticed a stiff lump in my right breast. I'm a very fastidious person. I've had different health problems before, a problem that can be considered important, it was not cancer, but it was a tumor in my lung. That's why I've always had regular checkups. I have small nodules on my breasts and I always have them checked too. When I felt it, of course, I panicked and got a checkup the very next day from hospital T (PHOPS). I went to the checkup and requested a breast ultrasound. In particular, I said that I was feeling a strange hardness in a very large area, there was a very strong tissue there that wasn't similar to a normal breast whatsoever, it was very stiff. The radiologist examined and said that there was nothing, those were a few benign lumps in my breast, which they call *fibroadenomas*. I already knew about them and I was getting them checked anyway. I asked them if they would recommend an additional examination such as mammography or MRI. They told me that there was no need. They also said that I couldn't get a mammography because I was under the age of 40. Indeed, when I didn't feel comfortable afterwards, I went to another hospital and asked for a mammogram because within 2 to 3 weeks my breast started to swell and hurt. I felt a few similar lumps in my armpit. It was even written in the ultrasound at that first checkup. I got very worried and went to hospital R (PHOPS). The general surgeon directed me to ultrasound first, when they saw the result, they wanted an MRI and then a biopsy. As soon as the biopsy result came, the diagnosis was made in 10 days. Unfortunately, since it couldn't be noticed in the first hospital at the beginning, the diagnosis was cleared with a delay of 3 weeks, and it was a situation that I could realize with my own efforts, materially and morally.

Patient 6-GSS (Appendix F, 9)

This quotation demonstrates that even in cases where patients immediately act upon symptoms of disease, the healthcare system itself may appear as a barrier to accessing timely and effective diagnosis, especially for younger patients. The second example within a small sample shows that delayed diagnosis is only due to the negligence of the patient, but there are barriers to diagnosis of breast cancer especially in younger women.

Although patients older than 40 can have an annual mammography scan provided by the MoH, none of them in my sample used this method. Most of them were not even aware of the existence of such a service.

As a case in point, Patient 2 depicts how her diagnosis was cleared as the following:

Of course, when I had first noticed it, I postponed it a bit because I'd gone to different health institutions about this before and it was clean every time, I've always gone to private health institutions by the way because I had a cystic breast type. Again, I didn't care too much about such a thing and went to a private hospital. They decided that I would have an ultrasound there, then mammography, and then a biopsy, all for a substantial fee, of course. Results came along in a rushed manner and I was told that it was an aggressive form of breast cancer.

Patient 2-GSS (Appendix F, 10)

As shown in the above quotation, this patient who does not have PHI chose to have screenings in private hospitals where they cost a substantial amount in order to get a timely and effective diagnosis. Furthermore, when I asked Patient 2 if she had ever researched into the contract status of the hospitals that she went to or had she ever considered benefiting from her GSS in those places, her answer was the following:

No, I didn't. I didn't have such a thought, but there was a contract (with SGK in place) in the hospital where I had my diagnosis cleared... But how much does that agreement... I mean, the state says it's providing something, but I haven't seen it done. We pay massive amounts for them, well, I paid massive amounts, so let me say that.

Patient 2-GSS (Appendix F, 11)

This quotation constitutes another example of not knowing how much the SGK pays, and even if it does, it being insignificant. In other words, in the patient's eyes, this is a private service in practice.

It can consequently be deduced from these narratives that the screening programs conducted by the MoH have not been implemented satisfactorily. To facilitate the effective implementation of such publicly provided services, family physicians in primary healthcare centers could ensure that the female citizens in their districts, at least those over the age of 40 according to the current regulation, are informed about these services, and provide guidance and direction in this regard,

which would be beneficial both in terms of protecting public health on a societal level and in terms of early diagnosis on an individual level.

Regarding the treatment process, the majority of patients using only GSS expressed their dissatisfaction with accessing treatment in PHOPS. For instance, Patient 12 several times mentioned how the treatment was very costly, which led me to formulate the follow-up question in a way as to underline that standard cancer treatment is entirely covered by GSS in Turkey, it is thus expected that patients do not pay any fees in private hospitals contracted with the SGK and asked about her experience in this matter. She uttered the following:

There is absolutely no such thing. If you don't have PHI, you must pay for treatment. You don't encounter a situation where you don't pay anything. Maybe it's because people don't prefer oncology departments as much or it's just the hospital policy... I shouldn't be Pollyanna on this matter. The way they call it may change; they may have made up a name for it. Let's assume that it may be expensive to visit an oncologist because you go through an examination, but this is also the case for the treatment protocol prepared afterwards. They gave me an appointment, I went in that day to receive treatment, – this is what I observed –, even though I did not meet with the doctor, – I say this because I know from my father's experience too –, even if you don't see the doctor, they register you in the system every time you go there, you pay a doctor's visit fee of about 500 liras for chemotherapy. I've had it frequently because it was an aggressive type, 500 liras for each session, once in every 2 weeks. That is to say, in normal circumstances, you should only be going there to receive chemotherapy.

Patient 12-GSS (Appendix F, 12)

The above quotation also constitutes an example of the aforementioned backdoor used by the PHOPS to manipulate the system, which allows them to charge for services that are supposed to be provided free of charge, such as chemotherapy. In this case, Patient 12 was obliged to pay a doctor's visit fee per session to receive chemotherapy despite the fact that she was not examined by the oncologist. In other words, as a GSS-only breast cancer patient, she could only access treatment by paying out of her pocket for a covered service. This indicates that one's entitlements

to a service both as a citizen and a patient are not conducive per se to the realization of those entitlements, thus impairing the publicness of that service.

Besides, notwithstanding that breast cancer patients access treatment in PHOPS through their GSS, many patients who participated in this study who only relied on GSS revealed their experiences of receiving treatment under poorer conditions in a PHOPS compared to those who use their PHI or pay extra fees for the same treatment. For instance, one of the patients explained the disparity amongst cancer patients based on their insurance statuses with respect to how they receive chemotherapy in PHOPS as the following:

Every procedure has a fee. For example, there is a special area on the second floor, a luminous place. Even the rooms where chemotherapy is received are different, even the rooms where those who receive treatment through the SGK and those who do not are different. There is second-class treatment in the hospital. Let me tell you about the basement floor, it is called B1, there is no light, you receive chemotherapy in a place with artificial lighting, but in private departments, places with direct fees or the rooms where people with private insurance take their medicine are in much more luxurious parts of the hospital, more comfortable.

Patient 7-GSS (Appendix F, 13)

The above quotation exemplifies that the insurance status of breast cancer patients plays a significant role in shaping patient pathways to treatment.

Overall, it is explicitly reported in the patient narratives that breast cancer patients encounter several obstacles in accessing treatment when they only rely on GSS. While these problems are mostly related to the cost of the treatment, in some cases they are associated with the effort and ability of patients to access integrated medical care as well as the quality of the service.

4.3 Factors affecting the bifurcation of treatment pathways

All participants in this study have accessed breast cancer treatment by following one of the two aforementioned pathways, but what do these pathways essentially mean in

terms of patients' access to quality treatment? To answer this question, this sub-section is dedicated to accounting for the two main factors that shape breast cancer patients' treatment pathways. These two distinct pathways are determined by a combination of two interrelated factors, the projected cost of cancer treatment and the effort and ability to access integrated medical care. The following quotation duly illustrates this interrelation:

So, of course, in general, it is much easier and more comfortable to receive services in a private hospital. Of course, if I had the means, I'd probably not go to the public [hospitals] for treatment again but I have to. Sometimes, for example, I still get my blood tests done in public hospitals, I get the injection in public hospitals too because, as I said, getting it in private [hospitals] is not sustainable. You know, I can give this money once or twice, but if I'm going to get this injection for 3 to 5 years, I can't give this money every month, it doesn't make any sense, so I continue to do the shuttling.
Patient 1-GSS (Appendix F, 14)

As indicated in the response of Patient 1, financial concerns emerge as a barrier to enjoying integrated medical care, that is, patients are bound to resort to different hospitals where the treatment they need is provided cheaper even though this entails roaming around various hospitals on a regular basis and/or experiencing lower quality healthcare. That is to say, despite that breast cancer patients are generally more eager to receive integrated medical treatment by a single provider if they could afford it, it becomes unsustainable at some point for some patients. As a result, they seek to access certain parts of their treatment either in cheaper private hospitals or public hospitals in accordance with their budgets.

4.3.1 The projected cost of cancer treatment

Cancer treatment is oftentimes long-lasting, that is, patients commonly receive treatment for many years. Therefore, patients who do not feel that their treatments

are covered by the GSS want to be able to project the cost of their treatment. For example, one of the patients with GSS stated that she needed to have an injection every month for the upcoming five years. She added that she was asked to pay for it and expressed discomfort with not being able to anticipate how much to pay for this treatment as follows:

180 liras [the fee paid for the injection], let's say 200 liras when you enter and exit the parking lot. This increases every year. Yes, I mean, we don't know how many percent it will increase next year. We pay whatever they want. We accept whatever they say.
Patient 2-GSS (Appendix F, 15)

As it is insinuated in the above quotation, the issue of “pricing” in healthcare is a highly complicated phenomenon. As such, many patients participating in this study, especially those without PHI, were at times in a position to make some kind of cost-benefit calculation in accessing treatment. For instance, one of the patients who had chemotherapy and breast surgery at different PHOPS described how she made a choice to determine where to continue the radiotherapy stage of her treatment.

They also tell you about the disadvantages, it was for radiotherapy [the hospital where the surgery was performed]. If the equipment is not modern, it may cause ambustions in the esophagus, the chest area is already newly stitched and ambustions may occur there too, the increase in temperature may cause wounds... When they talk about your life, you automatically think that it should be the latest technology so that you wouldn't suffer, but I couldn't think like that this time when I heard the 15 thousand liras. I never wanted to give this money and I continued radiotherapy in the previous hospital [the hospital where he received chemotherapy]. By the way, it was the same equipment. When I returned to my own hospital, I asked the name and code of the equipment out of curiosity, it was the exact same equipment.
Patient 12-GSS (Appendix F, 16)

As this quotation shows, the patient decided to go back to the hospital where she received chemotherapy because the price for radiotherapy exceeded her budget in the hospital where she was operated on. In other words, she made her decision based on

budget rather than quality. Besides, although the hospital where the surgery took place attempted to recruit her by claiming that they use the best equipment for radiotherapy, she later preferred to continue her treatment in a different hospital for a more affordable price and found out that the equipment used was the same. Hence, this narrative implies how the internal market for healthcare provision generally functions by the market logic and how the price of treatment is manipulated as any other product. In this specific example, it would be an understatement to describe it as "market logic" because it indicates a clear "deception" as the price is not standard even for the same service with the exact same machine in two different hospitals at the same time.

It would be proper to say that the above-mentioned narrative provides an exception in that given the subjective meaning attributed to cancer treatment, this study finds that overall, cancer patients' willingness to pay for treatment is noticeably high. For instance, another patient's narrative illustrates this trend as follows:

It was indeed an unbelievable amount of money being paid, and as far as I have observed, no one, no patient goes after this because people... As I said, at that moment, patient psychology comes into play and they try to survive. If they have money, they pay for it, if they don't, then it [surgery] takes place elsewhere. Actually, this is very interesting psychology; on the one hand, you are grateful to these people, yes, it is something that shouldn't be done [informal payments], but I can say that I love both the hospital and the doctors because they made me feel comfortable. You aren't able to think that you've spilled so much money, it's very different psychology.
Patient 6-GSS (Appendix F, 17)

Nevertheless, willingness to pay does not guarantee the ability to pay. The analysis here shows that the cost of treatment poses a significant barrier to accessing timely and effective quality treatment for breast cancer patients. This is because all patients who relied on GSS and some of those who held PHI with less coverage had to make

informal payments to PHOPS for standard breast cancer treatment, which is supposed to be provided on a free-of-charge basis.

To elaborate on this issue, one of the patients summarizes what kind of informal payments were demanded when she started her treatment as follows:

I'm paying. To begin with, there is a doctor's visit fee, which I pay once every 3 months. I also pay contributions. There is a fee for blood tests that I pay before each chemotherapy and a contribution fee that I pay for chemotherapy drugs. This fee varies depending on the length of your stay in the course of chemotherapy. For example, let's say you receive 4 hours of chemotherapy and they charge you about 300 liras per session. They call it the contribution fee. For example, if you receive treatment between half an hour and 1 hour, this fee drops to 200 liras. I don't know exactly why this is so, nor did I ask. I'm still paying contributions for MRI and tomography. I've never paid for PET; they say that it's all covered by the state. In general, I pay because they say that there is a difference in the procedures performed in private hospitals. Patient 11-GSS (Appendix F, 18)

This indicates that patients were informally requested to pay out-of-pocket fees to receive treatment under the name of "contributions" from which standard cancer treatment; chemotherapy, radiotherapy, and cancer surgery, is exempt according to the SUT. As a result, substantial inequalities in accessing treatment become surfaced, since not all patients enjoy the same financial resources to afford these payments to PHOPS, thus impeding the publicness of cancer treatment in Turkey.

Furthermore, while referring to informal payments, Patient 11 stated that she had not known exactly why this was the case, nor had she asked. This sentence alone exhibits the extent of information asymmetry between patients and healthcare providers. When it comes to such expensive treatments as breast cancer treatment, patients were mostly informed about the costs after they had received the treatment rather than before. For example, Patient 9 protested about how she was not informed about the costs until the end of her treatment, although she repeatedly asked for it. She stated:

Why didn't you say it in the first place? After all, everyone goes somewhere according to their budget. If you'd told me from the beginning, I'd have known that this wasn't within my budget and I wouldn't have received my treatment here. Why don't you tell me the price from the beginning? "This is our system", they say. Then you will be prepared for it when I can't afford it at the end. Since you don't tell me what to expect from the beginning, you are taking the risk of whether or not I have money at the end. If you told me from the beginning that "this is a treatment of 60 thousand liras, we don't know how much your insurance limit is", I'll check it and see on the internet, I have 15, 45 is missing, and if the SGK pays 8 thousand liras, it would be 32 for me. I would run away without looking back anyway!

Patient 9-GSS and PHI (Appendix F, 19)

As it is shown by the above quotation, the information asymmetry between breast cancer patients and healthcare providers was reinforced by another instance of the manipulation strategies used by the PHOPS as to choose when and under what circumstances to inform patients about the cost of treatment. It is also important to note that in an unregulated setting, this leverage of healthcare providers allows them to manipulate patients' choice of the healthcare provider to access treatment.

By the same token, the timeliness of information is key for enhancing patients' ability to access treatment. As a case in point, one of the patients expressed how the information on the treatment plan and costs were disclosed in such a way as to render her face with new costs in each step of her treatment. She stated:

For example, when making an appointment, they were telling me that the doctor's visit fee was this much. When I talked to them about radiotherapy, they informed me about when and how much they would charge, but when I was going to start the treatment, they didn't give me such an outline beforehand regarding how much to pay and when. It was always like when it's time or if it's necessary, last minute or something... It was a little bit like "step by step" information. I can't say that I was not informed, but since we learned about the surgery quite late and they had to do the surgery in a short time, I mean, we learned about the cost and I had to have the surgery within 2 weeks. So, I had to find 100 thousand liras in 2 weeks. This is rather late notice. Maybe we didn't ask, we didn't think about it, maybe it can be said that they didn't inform us, but when the patient is in that state, she is already receiving chemotherapy.

Patient 6-GSS (Appendix F, 20)

As the above quotation demonstrates, information asymmetry and timeliness of information related to the projected cost of cancer treatment are significant factors in shaping breast cancer patients' treatment pathways. They also have a causal relationship to other factors that appear as barriers to accessing integrated medical care for breast cancer patients, which will be detailed in the following sub-section.

4.3.2 Barriers to accessing integrated medical care

Many patients in this study were able to receive different parts of their treatment from the same healthcare institution, which facilitated their use of integrated medical care. For example, when I asked Patient 8 to account for her overall experience of breast cancer treatment, she expressed the following:

In a nutshell, I can say that everything was perfect. From the secretary to the radiotherapy technicians... Frankly speaking, the doctors are young, bright, intervening in everything in a timely manner, providing good treatment, and reassuring. Nurses are like that as well. Hospitals are very clean in the first place. In terms of services, the approach of the staff during the period from my hospitalization to my discharge, and then in the medical oncology and radiotherapy, was really remarkable. I think K (PHOPS) is a very advanced hospital in terms of cancer treatment. I go to K for all my procedures, check-ups, and monthly treatments. In terms of getting appointments and being able to reach my doctor during the follow-up process, they assured me that I could reach my doctor at regular intervals, be it by email or phone. Both after the surgery and before starting the chemotherapy, – this is a massive treatment as you may know – they informed me about nutrition as well as what I should do to take care of the area that would receive chemotherapy. I'd say that it was absolutely perfect.

Patient 8-GSS and PHI (Appendix F, 21)

As this quotation illustrates, Patient 8 received all major parts of her treatment (surgery, chemotherapy, and radiotherapy) in the same PHOPS, evaluated the hospital in terms of both physical properties and personnel, was satisfied with the service she received and did not encounter any difficulties in accessing treatment.

The overwhelming majority of patients in this study associated being able to access integrated medical care with their wellbeing over the course of their treatment pathway. The patients who only relied on GSS for their treatment also endorsed this view although they had to make informal payments to the PHOPS for their treatment. As a case in point, Patient 6 who only used GSS for her treatment in a PHOPS summarized the importance of integrated medical care as follows:

I think it has a positive impact because, from the very beginning of the process, doctors have been in control of the content of your disease. Doctors are in constant communication with each other, the surgeon directs you to the oncologist s/he knows, they talk constantly, the plastic surgeon calls the general surgeon and talks about you. In the councils, they discuss how this patient was like that 6 months ago, she will be like this in 3 months, right now she is like this, they dominate the whole process and I can say that I saw the advantage of this. The doctors say among themselves, for example, the oncologist says that you are the patient of that surgeon, okay, then he acts a little more interested and different. In that respect, I think it has a positive effect, getting treatment from one place. Also, I think it is a very reassuring feeling to have surgery done by the first surgeon you went to, so I didn't want to change the hospital right before the operation. I'm sure the other surgeon would do well too, but I don't know him. I don't know, I'll show up and tell them to operate me, you can't trust.
Patient 6-GSS (Appendix F, 22)

The notions of “trust”, “safety” and “comfort” regarding integrated medical care were very prominent in the eyes of breast cancer patients using private services and reoccurred in the interviews multiple times. For instance, when I asked Patient 2, who received treatment from different PHOPS if she would rather stick with the hospital where she first started her treatment, she replied as follows:

I would, of course, if it weren't for the financial burden. Even if you receive surgery and other treatments in separate places, you are still drawn into a bell. You want to have everything done there. You don't want to go out of it, let the hospital get to know you, you get to know the hospital. All done with one click. I don't have to tell them anything. If you think otherwise, I'll go elsewhere for something, I'll go elsewhere because of the money, I will go to another place to get it done, I will bring it back, give it to the secretary, he will scan it and load it there, so if the smallest thing is overlooked, if he hasn't scanned something, the doctor won't see it there, but otherwise they

can type in and look at everything from the screen. This sounds reliable to me. Patient 2-GSS (Appendix F, 23)

The above quotation shows the extent to which it is important for patients to feel as safe and comfortable as possible during breast cancer treatment, which implies getting the service from a single provider. Patient 2 also insinuated that she could not sustain her treatment in the same PHOPS due to persisting costs. Taking into account that cancer treatment often entails treatments that last months, if not years, cost-related barriers may impede patients' ability to receive integrated medical care consistently by a PHOPS.

In a different interview, Patient 12 explained the hardship with shuttling between multiple healthcare providers as follows:

This is a very difficult process, once you are there, then you are here. In the meantime, the assistants forget about your files, you keep sending files from one to another because the assistants forget about them, you manage the whole process as the patient, not the oncologist or surgeon. You have to repeat which patient you are and who you are at every turn, which makes these processes of shuttling very challenging.

Patient 12-GSS (Appendix F, 24)

As this quotation demonstrates, breast cancer patients not only consider managing the paperwork of their treatment as an additional burden but they may also find it difficult to repeatedly introduce themselves and their case to new people when they have to combine different providers.

On the other side of the coin, patients who had the means to receive an integrated medical treatment generally revealed positive experiences. For instance, Patient 10 reflected on her experience of receiving treatment in the same hospital as follows:

From my point of view, it was comfortable to receive treatment in the same hospital, because you're very tired, you're not in the mood to search, run, and

commute here and there. We didn't have a car at that time, many of my friends were going to receive chemotherapy by public transport, some of them got very serious infections during the chemotherapy stage. So, we pushed our luck a little bit, we went by taxi or by asking a friend. Apart from that, being in the same place also makes it easier for doctors to keep up with you. All doctors are in communication, and they make decisions together. This put me at ease and made me feel more confident. At least I didn't let it prey on my mind. Receiving treatment in the same place made me feel both safe and psychologically at ease.

Patient 10-GSS and PHI (Appendix F, 25)

In the above quotation, Patient 10 not only refers to the aspects of safety and comfort on the side of the patients when they access treatment in an integrated way but also not to have to make an effort to ensure the communication between the doctors in different branches about her case.

Overall, the difference between the experiences of those who held PHI and those who only relied on GSS in terms of accessing integrated medical care was that the costs did not appear as an important motif in the former's narratives whereas it was the most important determinant for the latter.

Finally, yet importantly, although it was not a prevalent theme found in the interviews, another important feature of the current healthcare system in Turkey was brought out by one patient's narrative. Despite breast cancer patients with PHI in my sample were largely able to receive integrated medical care from a single provider, the experiences of Patient 4 demonstrated that non-medical, social care is not integrated into this treatment:

There is something that works well in Turkey, I have no children, but if you were my daughter, you would probably stay with me during that period. This arrangement is common in Turkey. Mother-child, siblings, or friends, but everyone has a life, they have to work, no one can postpone life and take care of you. Someone is needed for this (referring to social care provision), that one means money, that's it.

... I worked until I was 58 years old, though I was retired, I had to work because I was divorced, I also enjoy working, so I made a budget as if I was

not getting any pension at that time. It was not great, but I appreciated it after this illness. I spent a very important part of it on the salary of the lady who came to help me.

Patient 4-GSS and PHI (Appendix F, 26)

In this quotation, Patient 4 states that although she had access to integrated medical treatment, as a single woman without children, she could only receive social care support thanks to her savings. This exceptional case shows that this feature of the healthcare system organization shapes breast cancer patient pathways regarding access to social care as well.

4.3.3 Shared obstacles

There are shared obstacles expressed by both groups of breast cancer patients despite the differences in their treatment pathways based on their insurance statuses. These are such issues that emerge during the follow-up stage. Regardless of the insurance type, when breast cancer patients receive the standard treatment, that is, breast surgery, chemotherapy, and radiotherapy, they are no longer considered as “cancer patients”. This poses many difficulties for patients because vital non-communicable diseases such as cancer may have enduring consequences even if the patient is technically cancer-free after the treatment. Thus, in the best-case scenario, breast cancer patients must go through annual controls including many tests and screenings such as MRI, PET scan, mammography, and such.

Patients who received treatment through GSS largely pointed out that the cost of cancer does not cease when the treatment is over. Once patients deal with cancer in their lives, they are usually considered “risky” patients for the rest of their lives. Therefore, they continue to face many cost-related problems after their treatment is completed because, as they are no longer considered as “cancer patients”, their GSS

does not fully cover many tests and screenings and the contribution fees for such services come into play in the PHOPS. To illustrate this issue, a patient explains the dialogue between her and her doctor a few months after her treatment was completed as follows:

[She was talking about the process after her treatment was completed] There is also this thing, for example, one day, when I said that my shoulder hurt, the doctor was very nervous, I mean, there are such things. Then, my doctor told me something like, “When you say that you have a pain in some place, I have to look into it, I mean, you're a risky patient now, I can't ignore it.” She requested an MRI. Anyway, the MRI was done, so it cost 2 thousand liras just for a shoulder MRI. You know, I think I have my annual check-ups in a month, for example, there will be a whole-body scan, I wonder how much I will pay.

Patient 2-GSS (Appendix F, 27)

As the quotation above indicates, patients who rely on GSS have almost no way of projecting the cost of their treatment during the follow-up stage in PHOPS.

Similarly, patients who primarily rely on their PHI for their treatment stress that as soon as their standard medical treatment was over, GSS did not provide a guarantee for the necessary tests and screenings during the follow-up stage, and PHI premiums drastically increased for those services after their treatment was complete. For instance, Patient 10 who used both GSS and PHI for her treatment explained this issue as follows:

... our work does not end there (where the treatment is completed). What about the next? Tests? Screenings? It is also quite distressing after the treatment, I don't know if there is a question about it, I have never heard of it. They speak of the treatment. Treatment is over! What will I do? Every 3 months, the doctor requests a PET, tests, mammography, an ultrasound, a gynecological examination... These? These are chargeable. The patient is the same though! Then when the treatment was over, did this patient get better, as if she had the flu? There is also this stage of this disease and this should also be guaranteed, the patient should not experience the stress of it. How will this work? It does not pay for my medicine, where can I find it? Should I sue? That's the sour part of this business. ... Post-treatment check-ups are also very important.

Patient 10-GSS and PHI (Appendix F, 28)

As these quotations manifest, even if patients receive breast cancer treatment in PHOPS through insured or underinsured pathways, they encounter common problems regarding their ability to access healthcare services in the stage of follow-up.

This reveals an important aspect of the current health system that should be criticized because, when patients lose their 'cancer patient' status, the cost of services in PHOPS increases exponentially, and the only way for patients to access these services that they cannot access in private hospitals will be to apply to public hospitals where they pay a smaller amount of contribution fee for such services. However, considering that access to screening services in public hospitals often takes weeks or months, this option is far from ideal for patients who are already in the risk group when it comes to non-communicable diseases for which early diagnosis is vital, such as cancer.

4.4 Conclusion

Using Turkey as a case study, this chapter elucidates how the healthcare system shapes breast cancer patients' treatment pathways. This study finds that the health insurance status of patients is indicative of their patient pathways to diagnosis and treatment in PHOPS. Two major patient pathways emerged from the analysis of the interviews, which differ based on two interrelated factors that substantially influenced breast cancer patients' diagnosis and treatment experiences, namely the projected cost of cancer treatment and barriers to accessing integrated medical care. In addition, common obstacles related to the stage of follow-up were identified in the experiences of all breast cancer patients irrespective of their health insurance type.

Breast cancer patient pathways were revealed by their healthcare-seeking behavior in the Turkish context of an internal market for healthcare provision. The analysis of their experiences and perceptions with regards to accessing treatment in PHOPS indicated that patients in this study have followed either an insured or underinsured pathway to breast cancer diagnosis and treatment. Insured patient pathways are primarily characterized by receiving integrated breast cancer care in PHOPS without financial concerns. The findings show that the common trait between the patients who followed an insured patient pathway is having a comprehensive PHI alongside GSS. On the other hand, underinsured patient pathways are remarkably represented by problematic experiences of accessing breast cancer diagnosis and treatment. All patients who only rely on GSS followed underinsured pathways, albeit to different extents. Considering that standard cancer treatment is universally covered by GSS on paper, this finding underlines a wide gap between statutory entitlements of patients and their actual experiences in the context of the internal market for healthcare provision in Turkey.

Five out of six patients who held PHI followed an insured patient pathway to diagnosis and treatment of breast cancer. Owing to their ability to afford the treatment in PHOPS by their PHI, they did not experience cost-related issues regarding medical care. Only the remaining patient encountered cost-related issues in a PHOPS because she was only favored with PHI by her employer in the middle of her treatment after she was diagnosed with breast cancer. Overall, these patients revealed smooth experiences in the PHOPS. None of them have known that they have a statutory right to free breast cancer treatment in the PHOPS.

Amongst all six patients who held PHI, five patients were by default considered as "private" patients by PHOPS, and they paid for their treatment by their

PHI. Only one patient was able to receive at least a sizable part of her treatment (chemotherapy and radiotherapy) through GSS and free-of-charge in a PHOPS. The findings reveal that none of these patients were provided with the option of using their GSS by the PHOPS whatsoever, the one who managed it followed the advice of her PHI agent. Most of these patients with PHI resorted to a maximum of two healthcare providers during the diagnosis and treatment stages of their illness, which enabled them to receive integrated medical care. The majority stated that this had a positive impact on their overall well-being over the course of coping with breast cancer.

The analysis of the experiences and perceptions of breast cancer patients regarding their diagnosis and treatment in PHOPS also brought underinsured patient pathways to light. Underinsured pathways are marked by obstacles related to the projected cost of cancer treatment by the PHOPS notwithstanding that standard cancer treatment (chemotherapy, radiotherapy, and breast surgery as listed in the SUT) is fully covered by GSS. Those who followed underinsured patient pathways were the ones who only had the means provided by GSS for accessing treatment in PHOPS.

There are different aspects to underinsured patient pathways followed by these patients. One of these aspects was the constant economizing by the GSS-only patients as to where and how they would receive treatment since the informal fees requested for services related to treatment varied from one PHOPS to another. When the cost of treatment projected by a certain PHOPS exceeded their budgets, they had to shuttle between public and cheaper private hospitals to access various treatments, which pointed to another aspect of underinsured pathways, namely the deprivation of integrated medical care.

Overall, the analysis here reveals that two interrelated factors shaped patient pathways to a large extent, namely the projected cost of cancer treatment and the effort and ability to access integrated medical care. These factors manifested a causal relationship, that is, the existence of issues related to the former almost certainly brings further issues regarding the latter.

Almost all patients who participated in this study were informally charged for their treatment despite their GSS. Overall, the projected cost of cancer treatment has been volatile in PHOPS. Unless the patient has PHI, the informal out-of-pocket payments that she made for certain services were constantly changing and she could not foresee how much the treatment would cost until it was complete. Considering that cancer often necessitates a prolonged treatment process, the unpredictability of costs posed a significant issue for breast cancer patients.

Informal payments appeared as the most common problem amongst patients who did not have PHI. As reflected by the perceptions of patients, their primary motivation was to recover as soon as possible when dealing with such a fatal illness. Thus, those who did not have PHI were still willing to pay for their treatment rather than filing a complaint despite the ambiguous treatment costs. That is to say, the subjective meaning patients attributed to cancer treatment affected their willingness to make payments to the PHOPS to access treatment.

Information asymmetry between breast cancer patients and healthcare providers was another barrier to accessing treatment in PHOPS as most of the informants did not possess necessary and accurate information regarding the validity of projected treatment costs by the PHOPS as well as their entitlements as patients and citizens.

Timeliness of information was another central issue that disempowered breast cancer patients vis-à-vis the PHOPS as much as informal payments and information asymmetry, the statements of the respondents demonstrate that patients were only informed about the costs when the PHOPS deemed appropriate or necessary.

In terms of access to integrated medical care, those who followed an insured patient pathway accounted for the advantages of receiving all of their treatment from the same hospital. In this context, some patients emphasized the feeling of safety and comfort that stems from creating a bond with the hospital and the medical staff within that hospital. Besides, patients mentioned that during such a long-lasting treatment process, it was easier for doctors in different branches to plan the treatment.

The burden of managing the paperwork related to one's treatment was a shared problem reflected by patients who could not access integrated medical care. As mostly indicated by underinsured pathways to treatment and diagnosis, those who only relied on GSS were in a disadvantaged position because the issues related to cost hindered their ability to receive integrated medical care in the internal market context of the Turkish healthcare system. For instance, when they had to shuttle between different hospitals to receive various treatments, they had to ensure the constant communication between doctors and administrative staff at different hospitals, gather and transfer all medical documents from one place to another and keep up with everything related to the course of their treatment.

The sustainability of integrated medical care was another significant problem despite its advantages. Some breast cancer patients relying only on GSS were no longer able to afford the treatment costs after a certain point in the PHOPS where they started their treatment. Consequently, they either resorted to public hospitals or

continued their treatment in other PHOPS where the same treatment is relatively cheaper. This reflects well the interconnectedness between the projected cost of treatment and barriers to accessing integrated medical care.

Lastly, yet importantly, all participants in this study expressed common concerns about the cost associated with the follow-up stage of their treatment regardless of their health insurance status. Many complained of excessive fees they paid for required annual checkups and screenings at PHOPS during that stage. Since breast cancer patients constitute a risk group that may need certain healthcare services more frequently than ordinary patients, the narrowness of the scope of cancer treatment that patients are exempt from additional fees has emerged as a common problem.

CHAPTER 5

CONCLUSION

Based on a small-scale qualitative exploratory study, this thesis provides insights into the experiences of breast cancer patients in terms of accessing diagnosis and treatment in the case of Turkey. The Turkish case is characterized by two components: 1) an internal market for the provision that includes public and private providers 2) a single-payer model that fully covers breast cancer treatment on paper. This thesis contributes to the literature by focusing on the salient experiences of breast cancer patients in accessing services that they are entitled to receive free of charge as Turkish citizens. It also displays what the experiences of breast cancer patients manifest about the *modus operandi* of the internal market for healthcare provision in the Turkish context through an account of patient pathways.

Patient pathways constitute a fresh research area in healthcare research, the existing literature on patient pathways largely demonstrates the medical perspective (Cherif et al., 2020). Studies focusing on how patients experience the healthcare system are limited in number (Rapport et al., 2019; Tremblay et al., 2015). Thus, this thesis contributes to the growing body of literature on patient experiences. It shows the ways in which the Turkish healthcare system shapes patient pathways into treatment. Moving beyond the generalist accounts (Yılmaz, 2020), I have taken a nuanced approach by focusing on a single patient group. Given healthcare benefits and patients' perceptions of their medical condition vary across different diseases, concentrating on a single patient group has provided a more in-depth examination of treatment pathways and their differentiation in the Turkish context.

This study also contributes to the nascent literature on patient experiences in accessing diagnosis and treatment of breast cancer (Anderson et al., 2006; Dye et al., 2010; Grosse Frie et al., 2018; Mousa et al., 2011). It is commonly found in this literature that patient pathways are diverse depending on the specific qualities of healthcare systems. The findings of this thesis corroborate those of this literature. In doing so, this thesis sheds light on what the experiences of breast cancer patients indicate about the functioning of the internal market for healthcare delivery in Turkey in the context of cancer patients' access to diagnosis and treatment. I argue that an internal market for the provision of healthcare reinforces rather than reducing the inequalities enmeshed in accessing breast cancer treatment in the Turkish healthcare system, which partly stems from a failure to provide effective public regulation. Drawing from Taylor-Gooby's (1999) framework of trust, I also argue that the publicness of cancer treatment has been amply eroded due to patients' willingness to apply to PHOPS (and to pay) combined with the ability of these providers to charge patients despite their statutory entitlements.

It may be explicit for social science researchers like myself that healthcare systems that we study have certain gender and class implications. As a case in point, breast cancer treatment is offered as a public service in Turkey. However, from an intersectional point of view on gender and class, the findings of this thesis show that although the current system appears to treat patients with all types of characteristics as the same, it ultimately leads to different repercussions for different patients. In other words, the current healthcare system could be considered gender inclusive in theory. However, it does not altogether eliminate social class differences in practice.

In line with this, I could not help but notice during the interviews that the burden of non-medical care did not appear as a pivotal issue in the context of the

Turkish healthcare system. This may at least in part be related to the familialist social care policies that have been enforced in Turkey, which put the non-medical care responsibilities almost completely on the family and women in particular. As one of the patient narratives mentioned in the previous chapter, when patients cannot rely on family to meet care needs, their only option is paid care services if only they can afford it, which drives me to the conclusion that the social care needs of certain citizens are still invisible in the current healthcare system.

Overall, this thesis identifies two patient pathways to diagnosis and treatment in PHOPS, namely insured and underinsured patient pathways. This naming was chosen in reference to the existing literature where patients who make excessive out-of-pocket payments to access treatment despite holding some form of insurance are deemed “underinsured” (Schoen et al., 2011). In congruence with this naming, this thesis finds that the health insurance status of breast cancer patients plays a decisive role in their pathways to diagnosis and treatment in the Turkish context. As the findings of this research indicate, a common pattern in the experiences of patients with PHI is problem-free experiences of accessing a timely and effective breast cancer treatment in PHOPS (insured patient pathways) whereas those who had only GSS revealed complicated and rather problematic experiences of accessing treatment in PHOPS (underinsured patient pathways). This study thus argues that patient pathways are by and large shaped by the healthcare system. In other words, different from the individualistic conclusions about patient pathways such as "every patient follows a unique path" (Lismont et al., 2016, p.126), the findings of this thesis demonstrate that healthcare system-mediated factors lead to the development of some shared patterns in patient pathways.

At first glance, these findings might appear counter-intuitive in such a country context where standard cancer treatment is fully reimbursed and universally covered. However, this thesis identifies the gap between the legal entitlements and the patient experiences. One key factor that generates this gap is that PHOPS are granted a spacious room for maneuvering in how they enroll patients in the hospital's system (as GSS holders, PHI holders, or private patients without any insurance), which opens a gateway for them to charge extra payments for fully covered services. This is previously highlighted by Yılmaz's (2020) leading study on patient experiences of healthcare provision in Turkey where informal payments and information asymmetry constituted barriers to accessing treatment in PHOPS, especially when patients needed urgent treatment or dealt with a complex disease that requires specialist services.

When it comes to breast cancer, a vital illness that often requires expensive treatment, costs might take on a different meaning for patients and their willingness to pay might increase considerably. In line with this, although Yılmaz's (2020) study on the Turkish context incorporates the access experiences of all patient groups whereas this research focuses on the salient experiences of breast cancer patients, the findings are consistent to a great extent. This thesis also finds that informal payments and information asymmetry with respect to the projected cost of cancer treatment constitute major barriers to accessing the diagnosis and treatment of breast cancer in PHOPS in Turkey.

What is more pronounced in this study, however, was that none of the patients who used their PHI knew or was informed by the PHOPS that she has the option to use GSS for the same treatment, except one patient who managed to use GSS at least partially with the advice of her PHI agent. In other words, the service

they received was also seen as a private service in the eyes of these patients.

Therefore, pertaining to Moulton's (2009) notion of "realized publicness", this thesis argues that the publicness of cancer treatment in PHOPS in principle is by no means reflected in the breast cancer patient pathways.

In addition to these factors, this thesis argues that particularly in the experiences of breast cancer patients, the timeliness of information stands out as another factor, which corroborates with the findings of Agarwal et al. (2007). This thesis finds that information about the course of the treatment and the expenses related to it were shared with breast cancer patients by the PHOPS is piecemeal. Considering the internal market in the Turkish healthcare system that compels patients to make cost-benefit analysis in accessing treatment and reach treatment with motivations similar to when choosing a product in the market, this study argues that patients should be able to access timely and proper information related to their treatment pathway in order to access quality medical care.

Furthermore, the literature on patient pathways in the field of oncology asserts that the specific setting in which patients receive cancer treatment impacts their health outcomes (Gaga-Bouchard et al., 2014; Onega et al., 2008; Huang et al., 2014). Since shuttling between multiple healthcare providers may encumber the integrality of care because of the efforts made and the time wasted for finding the most convenient service provider (Edward, 2005), accessing integrated medical care is especially relevant for breast cancer patients. In line with this literature, the findings of this thesis display that the bifurcation of breast cancer patient pathways in the Turkish context also emanates from whether or not patients are able to receive integrated medical care. Further research is needed to establish if this makes a significant impact on patient outcomes.

Patients who were able to access integrated medical care reflected upon its positive impact on their well-being in terms of fostering feelings such as safety, security and comfort whereas patients who accessed medical care in a fragmented way disclosed the difficulties with continuously managing one's treatment processes at the same time constantly looking for the cheapest and most appropriate treatment. This bifurcation is not far from the issues related to the cost of treatment because these two important factors manifest a causal relationship. Therefore, this thesis argues that when the cost of cancer treatment is no longer an issue for patients, patients can access integrated medical care in a single provider far more smoothly.

The findings of this study also shed light on a trade-off between establishing a single-payer system that offers UHC for such expensive services as cancer treatments by private providers and setting a low budget for healthcare. On the side of the state, anticipating for many years that private hospitals would deliver such services at considerably low reimbursement rates may have driven PHOPS to take advantage of other manipulation strategies in a loosely regulated setting. Consequently, there appears to be an implicit agreement between the state and private service providers on the functioning of the internal market, and the only party that truly suffers from this agreement is the patients.

Hence, the findings of this thesis provide evidence for the relevance of the previous assertions by Ağartan (2012) that the enlargement of the private sector in the provision of healthcare services necessitates such policies that endeavor to enact and perform effective regulation and by Yılmaz (2020) that the internal market for healthcare provision might go hand in hand with the aspiration for the publicness of healthcare services only if the state is eager and strong enough to regulate the system to address the current shortcomings adequately and effectively. However, it also

argues that regulation alone may not provide an ultimate solution to these issues if the overall budget set for healthcare in the country remains inadequate.

Ultimately, even though UHC has taken an important place in the agenda of both international organizations and governments in recent years, this study shows that accessing healthcare is important, but it is just as important to what patients access and under which conditions. The Turkish case demonstrates that we are able to learn the extent to which UHC is reflected in the experiences of patients through patient pathways.

Finally, there are certain limitations to this study. First, this is a small-scale qualitative study based in Istanbul where PHOPS are many and multifarious, therefore, its findings do not claim generalizability and representativeness to breast cancer patient experiences in Turkey. Second, this study only explores the experiences and treatment pathways of breast cancer patients who resorted to PHOPS, it would thus be useful for developing a more comprehensive understanding of breast cancer patient pathways in Turkey if further studies examine the experiences of patients who received treatment in public hospitals as well.

APPENDIX A

SEMI-STRUCTURED INTERVIEW QUESTIONS

Within the scope of this research, I aim to learn about your experiences related to healthcare services. During the interview, I would like to hear from which healthcare institutions you received your treatment from your diagnosis until the present time and the motivations behind your choice of these institutions, respectively.

1. Would you tell me a little about yourself? (How old are you, what is your profession, etc.)
2. How was the diagnosis made? Where did you receive the diagnosis?
3. Why did you choose this hospital/healthcare institution?
4. Did you have your further examinations (such as PET scan) done in the same institution during the diagnosis stage? (If no, where did you have it done? What was the reason you did not have it done in the same place?)
5. How did the process develop after your diagnosis was made? Did you plan your treatment with the same physician and health institution, or did you apply to another physician and/or health institution? If you applied to another physician and health institution to plan your treatment, why did you choose this path? (Being close to home, trusting the doctor/organization, costs, etc.)
6. What treatment plan was offered to you? (Surgery, chemotherapy, radiotherapy, drug therapy, etc.)
7. (If surgery, chemotherapy, and radiotherapy were recommended) Did you continue your treatment with the physician who gave you this treatment plan and in the health institution where you received the treatment plan? (If yes or no, what were your reasons for receiving your treatment with this physician and health facility?)

8. (If treatment is completed) Where and how did the follow-up process begin? How is it progressing/how did it end now?

9. Since cancer treatment in Turkey is completely covered by the General Health Insurance, it is expected that you do not pay any fees for cancer treatment in hospitals contracted with the SSI. How was your experience in this matter?

10. Which income group (lower, middle, upper-middle, upper) would you describe yourself as belonging to?

11. What could have been different when you consider your personal experience with healthcare services during the diagnosis, treatment, and follow-up stages? How could a better experience be provided?

12. (If the patient has received treatment from different healthcare providers) How did shuffling between different hospitals or healthcare institutions during the treatment process shape your experience? Would you prefer to receive treatment from a single health institution from the beginning to the end of the process? (If the patient received a significant part of their treatment from a single health service provider) How did receiving treatment from a single health institution during the treatment process affect your treatment experience?

APPENDIX B

SEMI-STRUCTURED INTERVIEW QUESTIONS (TURKISH)

Bu araştırma kapsamında sağlık hizmetleriyle ilişkili deneyimlerinizi öğrenmeyi amaçlıyorum. Mülakat boyunca tanı almanızdan bugüne kadar geçen süreçte hangi sağlık kuruluşlarından hizmet aldığınızı ve bu kuruluşlara gitmenizin ardında yatan nedenleri sırasıyla dinlemek istiyorum.

1. Öncelikle biraz kendinizden bahseder misiniz? (Kaç yaşındasınız, ne işle meşgulsünüz vb.)
2. Tanı nasıl kondu? Tanıyı hangi sağlık kuruluşunda aldınız?
3. Neden bu sağlık kuruluşunu tercih etmiştiniz?
4. Tanı sürecinde ileri tetkiklerinizi de (PET taraması gibi) aynı kuruluştaki mı yaptırmıştınız? (Hayırsa, nerede yaptırmıştınız? Aynı yerde yaptırmamanızın nedeni neydi?)
5. Tanınız netleştikten sonra süreç nasıl gelişti? Tedavi planınızı tanıyı koyan hekim ve sağlık kuruluşunda mı oluşturduysanız yoksa başka bir hekim ve sağlık kuruluşuna mı başvurduysanız? Tedavi planını oluşturmak için başka bir hekim ve sağlık kuruluşuna başvurduysanız, neden bu yolu tercih ettiniz? (Evine yakın olması, hekime/kuruluşa güvenmesi, kendisine maliyeti vb.)
6. Size nasıl bir tedavi planı sunuldu? (Ameliyat, kemoterapi, radyoterapi, ilaç tedavisi vb.)
7. (Ameliyat, kemoterapi ve radyoterapi önerilmişse) Tedavinize size bu tedavi planını veren hekimle ve tedavi planını aldığınız sağlık kuruluşunda mı devam ettiniz? (Evet veya hayırsa, tedavinizi bu hekimle ve sağlık kuruluşunda almanızın nedenleri nelerdi?)

8. (Tedavisi tamamlandıysa) Takip süreci nerede ve nasıl başladı? Şimdi nasıl ilerliyor/nasıl sonlandı?

9. Türkiye’de kanser tedavisi tümüyle Genel Sağlık Sigortası kapsamı içine alındığından bu yana SGK ile anlaşmalı hastanelerde kanser tedavisi için herhangi bir ücret ödemiyor olmanız beklenir. Bu konudaki deneyimleriniz nasıldı?

10. Kendinizi hangi gelir grubuna (alt, orta, üst-orta, üst) mensup olarak nitelendirirsiniz?

11. Tanı, tedavi ve takip sürecindeki sağlık hizmetlerine ilişkin kişisel deneyiminizi göz önüne aldığımızda neler daha farklı olabilirdi? Nasıl daha iyi bir deneyim sunulabilirdi?

12. (Eğer hasta farklı sağlık hizmeti sunucularından hizmet almış ise) Tedavi sürecinde farklı hastaneler veya sağlık kuruluşları arasında mekik dokumak deneyiminizi nasıl şekillendirdi? Sürecin başından sonuna tek bir sağlık kuruluşundan hizmet almayı tercih eder miydiniz? (Eğer hasta tedavisinin önemli bir kısmını tek bir sağlık hizmeti sunucusundan almış ise) Tedavi sürecinde tek bir sağlık kuruluşundan hizmet almak tedavi deneyiminizi ne yönde etkiledi?

APPENDIX C

CONSENT FORM

Supporting institution: Boğaziçi University

Title of the research: Breast Cancer Patient Pathways to Treatment in Turkish Internal Market for Healthcare: A Qualitative Study

Project Executive: Assoc. Prof. Volkan Yılmaz

E-mail address: vyilmaz@boun.edu.tr

Researcher's name: Zeynep Kesici

E-mail address: zeynep.kesici@boun.edu.tr

Dear respondent,

A scientific research project under the title of “Breast Cancer Patient Pathways to Treatment in Turkish Internal Market for Healthcare: A Qualitative Study” is being carried out by Assoc. Prof. Volkan Yılmaz, a faculty member of Boğaziçi University Social Policy Program, and Zeynep Kesici, a graduate student in Social Policy.

Since the advent of modern healthcare, healthcare systems have faced major changes and have become increasingly hybrid. Since the 2003 healthcare reforms, the Turkish healthcare system constitutes an example of this type of mixed healthcare delivery where there is an internal market for public and private healthcare providers along with a compulsory national health insurance scheme. In this context, certain healthcare services, such as cancer treatment, are universally covered. However, the problems arising from the existing barriers to accessing universally covered services warrant the importance of examining patient experiences in their ability to receive treatment in the internal market for healthcare provision in Turkey. Breast cancer patients often need comprehensive cancer treatment that includes a variety of medical interventions, from specific diagnoses to surgery, radiotherapy, and chemotherapy. Breast cancer is a widespread yet treatable disease and the most prevalent type of cancer among women worldwide. Drawing from the existing literature on treatment pathways for breast cancer patients, this thesis explores the perspectives of breast cancer patients on their treatment experiences and treatment pathways in private hospitals offering publicly funded services in Turkey. Patients' experiences of access to treatment will be analyzed in the context of the Turkish health system.

Consent: As part of this research, we invite you to conduct an interview that will take approximately 1 hour. We would like to inform you about the research before your decision. If you agree to participate in the research, we will conduct an interview that contains 12 questions with you. All personal information, your name, and contact information that you will share with us during the interview will not be shared with

anyone. Your personal information will be kept completely confidential. Your answers will not be attributed directly to you.

Participation in this research is completely voluntary and you will not be paid or rewarded for your participation in the study. Even if you initially consent to participate in this study, you have the right to withdraw from the study at any stage without providing any reason. You can opt out of participating in the study at any time. You do not have to answer questions you do not want to answer. After the interview, if you change your mind and wish to withdraw from the research, please contact us.

It is necessary to audio-record the interviews so that the experiences and opinions you convey are reflected correctly. Voice recordings will be transcribed by anonymizing names and personal information in order to protect confidentiality. Audio recording files and transcripts of audio recordings will be destroyed after the work is completed.

It is expected that the research will benefit society and academic studies in the future in the context of breast cancer patients' experience of accessing treatment in private hospitals within the scope of SSI. This research is not expected to pose any risk to you. However, we can interrupt or postpone the meeting at any time during the meeting according to your wish. If you state that you withdraw from the study, the interview records will be deleted and will not be used for scientific evaluations based on the research.

Considering that the interview contains some questions that may trigger emotions, it was deemed appropriate to share the contact information of institutions providing free psychological support with you. You can use the Ministry of Health Communication Center (SABİM) Hotline (184) to get more detailed information about the services.

- Community Mental Health Centers affiliated to the Istanbul Provincial Health Directorate under the Ministry of Health
istanbulism.saglik.gov.tr

- Wellness Centers affiliated to the General Directorate of Public Health within the Ministry of Health
shm.saglik.gov.tr

Before signing this form, please ask if you have any questions about the research. If you have any questions later, you can contact the project coordinator (Assoc. Dr. Volkan Yılmaz, Office Phone: 02123597564). You can also consult The Ethics Committee for Master and PhD Theses in Social Sciences and Humanities (SOBETİK) at Boğaziçi University (sbe-ethics@boun.edu.tr) about your rights regarding research.

If your address and phone number change, please let us know.

I approve of the audio recording. ☐

I understood what was told to me and what was written above. I have/don't want to have a copy of this form (in which case the researcher keeps this copy).

I agree to participate in the study.

Participant Name-Surname:

Signature:

Date (day/month/year):/...../.....

APPENDIX D

CONSENT FORM (TURKISH)

Araştırmayı destekleyen kurum: Boğaziçi Üniversitesi

Araştırmanın adı: Türkiye Sağlık Hizmetleri İç Pazarında Meme Kanseri Hastalarının Tedaviye Erişim Patikaları: Nitel Bir Araştırma

Proje Yürütücüsü: Doç. Dr. Volkan Yılmaz

E-mail adresi: vYilmaz@boun.edu.tr

Araştırmacının adı: Zeynep Kesici

E-mail adresi: zeynep.kesici@boun.edu.tr

Sayın katılımcı,

Boğaziçi Üniversitesi Sosyal Politika Anabilim Dalı öğretim üyesi Doç. Dr. Volkan Yılmaz ve Sosyal Politika Anabilim Dalı Yüksek Lisans öğrencisi Zeynep Kesici tarafından “Türkiye Sağlık Hizmetleri İç Pazarında Meme Kanseri Hastalarının Tedaviye Erişim Patikaları: Nitel Bir Araştırma” adlı bilimsel bir araştırma projesi yürütülmektedir.

Modern sağlık hizmetlerinin ortaya çıkışından bu yana, sağlık hizmetleri sistemleri büyük değişikliklerle karşılaştı ve giderek daha hibrit hale geldi. 2003 sağlık reformlarından bu yana, Türk sağlık sistemi, zorunlu ulusal sağlık sigortası programı ile birlikte kamu ve özel sağlık hizmeti sağlayıcıları için bir iç pazarın olduğu bu tür karma bir sağlık hizmeti sunumunun bir örneğini oluşturmaktadır. Bu bağlamda, kanser tedavisi gibi belirli sağlık hizmetleri evrensel olarak kapsanmaktadır. Bununla birlikte evrensel olarak kapsanan hizmetlere erişimin önündeki mevcut engellerden kaynaklanan sorunlar Türkiye’de sağlık hizmeti sunumu için iç pazarda tedavi alma becerilerinde hasta deneyimlerini incelemenin önemini garanti etmektedir. Genellikle meme kanseri hastaları özel teşhislerden ameliyata, radyoterapi ve kemoterapiye kadar çeşitli tıbbi müdahaleleri içeren kapsamlı kanser tedavisine ihtiyaç duyuyorlar. Meme kanseri yaygın fakat tedavi edilebilir bir hastalık olmanın yanı sıra dünya çapında kadınlar arasında en sık görülen kanser türüdür. Bu tez, meme kanseri hastalarının tedavi yollarına ilişkin mevcut literatüre dayanarak, meme kanseri hastalarının Türkiye’de kamu tarafından finanse edilen hizmetler sunan özel hastanelerdeki tedavi deneyimlerine ve tedavi yollarına bakış açılarını araştırmaktadır. Hastaların erişim deneyimleri Türk sağlık sisteminin temel özellikleri ışığında analiz edilecektir.

Onam: Bu araştırma kapsamında sizi yaklaşık 1 saat sürecek olan bir mülakat gerçekleştirmeye davet ediyoruz. Kararınızdan önce araştırma hakkında sizi bilgilendirmek istiyoruz. Araştırmaya katılmayı kabul ettiğiniz takdirde sizinle 12 soruluk bir mülakat gerçekleştireceğiz. Mülakat sırasında bizimle paylaşacağınız tüm kişisel bilgiler, isminiz ve iletişim bilgileriniz herhangi biriyle paylaşılmayacak,

arařtırmada sırasında ve arařtırmanın ıktısında isminize atfedilebilecek ya da sizi dođrudan iřaret edecek bir bilgiye hibir řekilde yer verilmeyecektir. İsminiz ve bu bilgiler tamamen gizli tutulacaktır. Aktarımlarınız dođrudan size atfedilmeyecektir.

Bu arařtırmaya katılmak tamamen isteđe bađlıdır ve alıřmaya katılımınız karřılıđında size herhangi bir ücret veya ödöl verilmeyecektir. Bu alıřmaya katılmaya onay verdiđiniz takdirde alıřmanın herhangi bir ařamasında herhangi bir sebep göstermeden alıřmadan ekilme hakkına sahipsiniz. İstedięiniz zaman alıřmaya katılmaktan vazgeebilirsiniz. Cevap vermek istemedięiniz soruları cevaplamak zorunda deđilsiniz. Görüşme sonrasında, fıkřınızı deđiřtirir ve arařtırmadan ekilmek isterseniz lütfen bizimle bađlantıya gein.

Aktardıđınız deneyimlerin ve görüşlerin dođru yansıtılması iin mülakatların ses kaydına alınmasına ihtiya duyulmaktadır. Ses kayıtları gizliliđin korunması aısından isimler ve kiřisel bilgiler anonim hale getirilerek yazıya aktarılacaktır. Ses kayıt dosyaları ve ses kayıtlarının yazıya dökölmüş halleri alıřma tamamlandıktan sonra imha edilecektir.

Arařtırmanın ileride meme kanseri hastalarının SGK kapsamında özel hastanelerde tedaviye eriřim deneyimleri bađlamında topluma ve akademik alıřmalara yarar sađlaması beklenmektedir. Gerekleřtirmek istediđimiz arařtırmanın sizin iin bir risk oluřturması beklenmemektedir. Ancak görüşme sırasında diledięiniz anda görüşmeyi kesebilir ya da erteleyebiliriz. Görüşmekten veya alıřmaya katkı vermekten vazgetiđinizi belirttiđiniz takdirde görüşme kayıtları silinecektir ve arařtırma üzerinden yapılacak bilimsel deđerlendirmeler iin kullanılmayacaktır.

Mülakatın duyguları tetikleyebilecek bazı sorular ierdiđi dikkate alındięında, ücretsiz psikolojik destek sađlayan kurumların iletiřim bilgilerinin sizinle paylařılması uygun görölmüştür. Hizmetlerle alakalı daha detaylı bilgi edinmek iin Sađlık Bakanlıđı İletiřim Merkezi (SABİM) Danıřma hattını (Alo 184) kullanabilirsiniz.

• Sađlık Bakanlıđı bünyesindeki İstanbul İl Sađlık Müdürlüğü'ne bađlı Toplum Ruh Sađlıđı Merkezleri

istanbulism.saglik.gov.tr

• Sađlık Bakanlıđı bünyesindeki Halk Sađlıđı Genel Müdürlüğü'ne bađlı Sađlıklı Yařam Merkezleri

shm.saglik.gov.tr

Bu formu imzalamadan önce, alıřmayla ilgili sorularınız varsa lütfen sorun. Daha sonra sorunuz olursa, proje yürütücüsüne (Do. Dr. Volkan Yılmaz, Ofis Telefonu: 02123597564) sorabilirsiniz. Arařtırmayla ilgili haklarınız konusunda Bođazii Üniversitesi Sosyal ve Beřeri Bilimler Yüksek Lisans ve Doktora Tezleri Etik İnceleme Komisyonu'na (SOBETİK) (sbe-ethics@boun.edu.tr) danıřabilirsiniz.

Adres ve telefon numaranız deęiřirse, bize haber vermenizi rica ederiz.

Ses kaydı alınmasını onaylıyorum. ☐

Bana anlatılanları ve yukarıda yazılanları anladım. Bu formun bir örneęini aldım/almak istemiyorum (bu durumda arařtırmacı bu kopyayı saklar).

Çalıřmaya katılmayı kabul ediyorum.

Katılımcı Adı-Soyadı:.....

İmzası:.....

Tarih (gün/ay/yıl):...../...../.....

APPENDIX E

ETHICS COMMITTEE APPROVAL FORM

Evrak Tarih ve Sayısı: 03.11.2021-36957

T.C.
BOĞAZİÇİ ÜNİVERSİTESİ
SOSYAL VE BEŞERİ BİLİMLER YÜKSEK LİSANS VE DOKTORA TEZLERİ ETİK İNCELEME
KOMİSYONU
TOPLANTI KARAR TUTANAĞI

Toplantı Sayısı : 22
Toplantı Tarihi : 13.10.2021
Toplantı Saati : 14:00
Toplantı Yeri : Zoom Sanal Toplantı
Bulunanlar : Prof. Dr. Ebru Kaya, Prof. Dr. Fatma Nevra Seggie, Dr. Öğr. Üyesi Yasemin Sohtorik İlkmen
Bulunmayanlar :

Zeynep Kesici

Sosyal Politika

Sayın Araştırmacı,

Daha önce onay almış olan SBB-EAK 2021/23 sayılı eski başlığı "A qualitative study on breast cancer patient pathways to treatment in Turkish internal market for healthcare" olan projenizin başlığının "Breast cancer patient pathways to treatment in Turkish internal market for healthcare: A qualitative study" olarak değiştirilmesi komisyonumuz tarafından 13 Ekim 2021 tarihli toplantıda incelenmiş ve SBB-EAK 2021/68 sayı ile kabul edilmiştir.

Bu karar tüm üyelerin toplantıya çevrimiçi olarak katılımı ve oy birliği ile alınmıştır. COVID-19 önlemleri kapsamında kurul üyelerinden ıslak imza alınmadığı için bu onam mektubu üye ve raportör olarak Fatma Nevra Seggie tarafından bütün üyeler adına e-imzalanmıştır.

Saygılarımızla, bilgilerinizi rica ederiz.

Prof. Dr. Fatma Nevra SEGGIE
ÜYE

e-imzalıdır
Prof. Dr. Fatma Nevra SEGGIE
Raportör

SOBETİK 22 13.10.2021

Bu belge 5070 sayılı Elektronik İmza Kanununun 5. Maddesi gereğince güvenli elektronik imza ile imzalanmıştır.

APPENDIX F

QUOTATIONS IN TURKISH

1. “Ben X'e (özel bir poliklinik) gitmiştim. Niye X'e gidiyorum? Yaklaşık 25 senedir benim rutin kontrollerimi yaptırdığım bir görüntüleme merkezi. Niye orada yaptırıyorum? Ben özel sağlık sigortası yaptım kendime 90'lı yıllarda, hep de ödedim rutin şekilde. Onun kadınlara verdiği free haktır, senede bir kere mamografi, ultrason ücretsizdir.” (P4-GSS ve PHI)
2. “Tasadüfen elime geldi sol mememde bir kitle, koltukaltına yakın bir bölge olduğu için böyle incelen bir deri, o tarafta tesadüf eseri elime geldi. K hastanesinde (Anlaşmalı özel) bir doktora gittim, orada bir cerraha muayene oldum, meme cerrahıydı, genç de bir doktordu. Çok ciddi bir şey olmayabileceğini ama yine de bir ultrason ve biyopsi yapmamız gerektiğini söyledi, daha net görebilmek için tabii ki. Ben ultrasonu çektirdim ama böyle çok bir hafta arayla tekrar gidip gelmem gerekiyordu falan, yani COVID inanılmaz bir durumdaydı, hastaneler, yoğun bakım dolup taşıyordu geçen sene Nisan'da yani. Düşünün. Öyle olunca ben biraz böyle tek gidip gelmekten çekindim ve biyopsiyi biraz erteledim. ... Böyle bir elimle tekrar yokladığımda biraz büyümüş gibi geldi bana. Hemen tekrar bir ultrason ve akabinde biyopsi, çünkü ultrasonun da üstünden bir 4 ay geçmişti. Onu da şöyle söyleyeyim, gerçekten çok şanslıyım, çok iyi bir girişimsel radyoloğa denk geldim, profesördü K hastanesinde. Mucizevi bir şekilde çok küçük, daha yeni oluşmuş bir kanser hücresinin etrafına yaydığı minik bir hücreyi, yani mikroskobik bir şeyi, öyle bir dokuyu bulup, yakalayıp, aldı. O benim için çok büyük bir şans oldu, burada hakikaten biyopsinin çok önemi var, biyopsiyi yapan doktorun yetkinliğinin çok önemi var. Onu yakalamak maharet ister yani gerçekten çünkü benim kitlem, yani bende ki kitle bir santimin altındaydı, dolayısıyla bu benim için çok büyük bir şans oldu, çok erken tanı konmuş oldu aslında.” (P3-GSS ve PHI)
3. “Q hastanesindeki (Özel) doktor bize dışardan M (Anlaşmalı özel) adında bir tıp ve görüntüleme merkezinde bakıyordu. Orada baktı bana da tanı için. Şu an hala borçlarımı ödüyorum hastalığımın, öyle diyeyim, hala o zamanlardan çektiğimiz krediler devam ediyor, kredi kartları, bitmedi yani. Bir biyopsi için 3 bin 500 lira vermiştim, bana 3 kere yapıldı ki tanıdık doktor olmasına rağmen, bizden lüzumsuz bir para alınmadı yani buna eminiz, çok yakın bir aile dostumuzun tanıdığı, artık PET'i ücretsiz nerede yaptırabiliriz, neyi ne şekilde halledebiliriz bunları araştırdı bizim için. Bir de soyup soğana çevirenlerin eline düşseydik herhalde şu anda ben borç batağındaydım. A Hastanesi'nde zaten görüntüleme yaptırmanıza imkan yok, tek bir görüntüleme 10-15 bin lira civarı. Biz M'de birkaç tanesini SGK üzerinden yaptırarak, bir de G hastanesi (Anlaşmalı özel), diye bir yere yolladılar bizi orada PET çekimine hiç para ödemedik, SGK karşıladı, biyopsileri ödedik. Doktorun muayenesi de vardı tabii, bir muayene 600 lira neredeyse.” (P9-GSS ve PHI)

4. “İlk öğrendiğimde [hastalığı] tabii çevremde herkes bir anda böyle doktor tavsiye etmeye başladı, bir kaos süreci oldu. Herkes ‘Buna kesin git!’ diyordu. O sırada Q Hastanesi’nde (Özel) bir meme cerrahı tavsiye edildi bana. İlk gittiğimde sadece SGK vardı, Ocak ayında özel sigortam yapılacaktı, Kasım-Aralık ayı o yüzden hep ekonomik olarak bizi zorlayan süreçlerle geçti, biyopsiler, ultrasonlar, arka arkaya gelen mamografiler... Bazılarını uygun fiyatlı özel hastanelerde yaptırdım, bazıları için devletten randevu aldım, görüntülerini beğenmediler, hiç iyi bulmadılar, mecburen tekrar iyi bir yerde yaptırmam gerekti.” (P9-GSS ve PHI)
5. “O anda görünen ameliyat artı radyoterapiydi. Sonra neyse ben ameliyatımı oldum, çok iyi bir ameliyat oldu, gayet de memnun kaldım, meme koruyucu yapıldı zaten, sadece o kitle alındı. İyi de bir şeydi, çok rahat ettim, bir gece kaldım, hiç para ödemedim, onu özel sağlık sigortam karşıladı B hastanesinde (Anlaşmalı özel). Neyse çok şükür ameliyatımı oldum, bitti, fakat patoloji böyle çıktı, patolojiden sonra dedi ki cerrahım, 'Biraz yüksek agresyonu olan ve derecesi 3 olan bir kitle ile karşı karşıya kaldık, koruma amaçlı bir kemoterapi yapmamız gerekecek' dedi. Onkologla görüşürdü beni o evrede. Ben sonra bir onkologla B’de bir araya geldim, XX doktorun ismi, sağ olsun çok ilgili ve iyi bir doktordu. Anlattı her şeyi, hiçbir zaman böyle şey değildi, gerçekçi oldu yani. Kemoterapi beklemiyordum ama oldum, 4 seanstı o da. B’de aldım onu da. Gayet iyi koşullardaydı, hiçbir şekilde hiçbir sıkıntı yaşamadım, çok steril, temiz, özenli. Doktorlar da öyleydi, psikolog vardı, geliyordu her seferinde ziyaret ediyordu, diyetisyen geldi birkaç kere, beslenmeyle ilgili kemoterapi esnasında bilgi verdi, klinik psikolog periyodik olarak uğruyordu.” (P3-GSS ve PHI)
6. “Ben kemoterapi ilaçlarım özel hastanede olmama rağmen özel sağlık sigortamın yükünü biraz hafifletmek manasında sigorta şirketimin yönlendirmesiyle SGK üzerinden aldım. O semtinde anlaşmalı birkaç tane eczane varmış, onlar benim kemoterapi ilaçlarımı hazırladılar ve bana eve kadar getirdiler. Ben de onlar A (Anlaşmalı özel) hastanesine teslim ettim ve kemoterapiyi bu şekilde aldım. Radyoterapiyi için de A’daki radyoterapi doktoru SGK anlaşmalı bir doktordu, özel sigortam da ödemiş oldu onu. O işlemi ben SGK’dan faydalanarak yaptırdım A’da. Haplarımı da yine hastanenin yönlendirmesiyle onların SGK anlaşmalı bir doktorundan rapor çıkartarak bundan sonra SGK’dan alabileceğimi söylediler. Sağlık ocağından o raporumla 3 aylık ilaçlarımı alabiliyorum. Şimdi pandemi döneminde oraya gitmeye bile gerek kalmıyor eczanelerin sistemine düştüğü için onlar da görüp vakti geldiğinde veriyorlar. Bu anlamda da hiç sıkıntı yaşamadım.” (P5-GSS ve PHI)
7. “Radyoterapi her gün alınacak olunca ve iş yeri de artık izinler konusunda sıkıntı çıkarmaya başlayınca ben öğle tatillerinde gidebileceğim bir hastane aramaya başladım. Öğle tatilinde gidebileceğim ve 1 saat içinde işe dönebileceğim E hastanesi (Anlaşmalı özel) vardı. Orada bir radyolog önerdiler bize ve gittik görüştük. 32 ya da 34 seans, öyle bir şey önerdi. Haftada 5 gün, hafta sonu yok. Ben her öğle tatilinde koştur koştur metroya binerek hastaneye gittim ve oradan tekrar işe dönerek geçirdim o süreci. İlk bankoya gittiğimde de sigortamın limitleri olduğunu söyledim. Sonuçta A’da

(Özel) kemoterapi çok ciddi bir rakamdı ve bu düştü zaten benden. Tedavinin ne kadar tutacağını sordum. 30 seans hani, 20 bin lira, 30 bin falandır... Bana fiyatını söyleyin dedim, ‘Sorun değil, zaten bir kısmını SGK karşılıyor, alamadığımız kısmını SGK'dan alırsınız’ dediler. Hiç rakam yok bu sırada, şunu SGK öder, şunu özel sigortanız öder falan yok. Fiyat öğrenemedim. Bitiminde biz size bilgi veririz ama merak etmeyin zaten ikisinden birinden yararlanırsınız, bu tedaviye yeter dediler. Tamam mı, tamam. İmzalar atıldı. Son radyoterapiyi aldım. Bankodaki kız böyle ne yapacağını bilemez bir halde, 'Ben sizi bir böyle alabilir miyim?' dedi. Elinde kağıtlar falan var, provizyonumu aldıklarını, bana 32 bin 800 lira ödeme çıktığını söyledi. Ben böyle bir anda kıpkırmızı oldum, tansiyonum çıktı. ‘Ne kadar?!’ dedim. Herhalde sigortanın karşıladığı kısmı söylüyordur... Size düşen 32 bin 800 lira diye tekrarladı. Siz dalga mı geçiyorsunuz benimle dedim. ‘Bu ne kadar bir rakamdı ki 32 bin 800 lirası bana düştü?’ diye sordum. Sigorta limitimin 15 bin lira kalmış, SGK'dan yalan olmasın 5-6 bin lira kadarı ödenmiş, geriye de 32 kalmış! 60 falanmış toplamda. Benim böyle bir param yok yani!” (P9-GSS ve PHI)

8. “Kendim banyoda elle kontrol ederken bir kitle fark ettim göğsümde ama kanser olmaz diye düşündüm çünkü ailemde hiç yok ve 40 yaşın altına mamografi çekilmediğini bildiğim için demek ki 40 yaşın altındaki insanlar pek de olmuyor diye düşündüm ve bir 6,7 ay kadar bu konuyla ilgili hiçbir şey yapmadım. Tabii ki kötü bir şey olmasından korktuğum için de doktora gitmedim ama bu mamografi yaşı gerçekten kararımı etkiledi bu noktada. Daha sonra koltuk altımda da bir o kadar büyük bir kitle bulduğumda çok korktum ve doktora gittim.” (P1-GSS)
9. “Kasım ayında ben sağ göğsümde bir sertlik fark ettim. Çok pımpirikli bir insanımdır ben. Daha önce de farklı sağlık sıkıntıları yaşadım, önemli sayılabilecek bir sıkıntı, kanser değildi ama bir tümördü akciğerimde. O yüzden ben düzenli checkup yaptıran bir insandım. Memelerimde de küçük nodüller vardı onları da takip ettiriyordum. Tabii böyle bir sertlik görünce çok panikledim ve hemen ertesi güne checkup almıştım, burada T Hastanesi (Anlaşmalı özel) var. Checkupa gittim ve meme ultrasonu istedim. Özellikle de dedim ki ben burada çok geniş bir alanda tuhaf bir sertlik hissediyorum, normal memenin olamayacağı kadar kuvvetli bir doku var burada, çok sert. Oradaki radyolog baktı ve bir şey yok dedi. Bunlar memenizdeki birkaç tane fibroadenom dedikleri iyi huylu kitleler dedi. Zaten bunu biliyordum ve takip ettiriyordum. Ben de mamografi veya MR gibi ek bir tetkik yaptırmamı tavsiye edip etmediklerini sordum. Gerek yok zaten 40 yaş altı olduğunuz için mamografi çekmezler size dedi. Gerçekten de ben daha sonra içime sinmeyince başka bir özel hastaneye gittim ve mamografi istedim çünkü 2-3 hafta içerisinde benim memem şişmeye ve ağrımaya başladı. Zaten koltuk altımda bir yumru hissetmiştim. Hatta o checkuptaki ultrasonda da yazılmıştı bu. Meme şişmeye ve ağrımaya başlayınca iyice telaşlandım ve R Hastanesine (Anlaşmalı özel) gittim. Genel cerrah beni önce ultrasona yönlendirdi, sonucu görünce MR istediler ve MR'dan sonra da biyopsi istediler. Biyopsi sonucu geldiğinde 10 gün sona tanı konulmuş oldu. Maalesef tanı ilk başta gittiğim hastanede fark edilemediği için 3 haftalık

gecikmeyle gelmiş oldu ve o da benim maddi manevi kendi çabalarım ile gerçekleştirdiğim bir durum oldu.” (P6-GSS)

10. “İlk fark ettiğimde biraz öteledim tabii ki çünkü daha önce de bununla ilgili farklı sağlık kuruluşlarına gitmiştim, hep özel sağlık kuruluşlarına müracaat ettim bu arada çünkü kistik bir meme yapısına sahiptim, ona rağmen her seferinde temizdi. Yine böyle bir şeydir diye çok üstünde durmayıp yine özel bir hastaneye müracaat ettim. Orada bir ultrason, ondan sonra mamografi, ondan sonra da biyopsi olmama karar verdiler, ciddi bir ücret karşılığı tabii bunların hepsi. Bir koşturma içerisinde bunlarla beraber sonuç geldi ve agresif bir meme kanseri türü olduğunu söylendi.” (P2-GSS)
11. “Hayır. O düşünceyle gitmemiştim ama ilk gittiğim, teşhisi koyan hastanede öyle bir anlaşma vardı ama anlaşmada ne kadar... Yani hani devlet karşılıyor diyor ya bir şeyleri, ben karşıladığımı görmedim. Büyük rakamlar veriyoruz biz bunlara, büyük rakamlar verdim yani öyle söyleyeyim.” (P2-GSS)
12. “Kesinlikle böyle bir şey yok. Siz özel sağlık sigortanız yoksa kesinlikle para ödemek zorundasınız. Ödenmediği gibi bir durumla karşılaşmıyorsunuz. Belki insanlar çok fazla onkoloji bölümünü tercih etmiyorlar ya da hastane politikası böyledir, çok Pollyanna bakmayayım bu duruma bu konuda. Bunun adı değişebiliyor, adını bir şeye uydurmuş olabiliyorlar. Atıyorum, normalde onkoloğa ulaşmak ücretli olabilir çünkü bir muayeneden geçiyorsunuz ama sonrasında hazırlanan tedavi protokolünde de bu böyle. Bana gün verildi, o gün gittim tedaviye, -gözlemlediğim şey buydu-, doktoru o gün görmesem bile, -babamdaki deneyimlerimden de bildiğim için söylüyorum bunu-, doktoru görmeseniz bile size bir kayıt açılıyor ve siz her oraya gittiğinizde kemoterapi için, -agresif cinste bir durum olduğu için ben sıklıkla gördüm, 2 haftada 1 seans-, o yüzden 2 haftada bir yaklaşık 500 lira gibi bir doktor vizite ücreti ödüyorsunuz. Yani, normal şartlarda oraya sadece kemoterapi ilacını almak için gitmeniz gerekiyor.” (P12-GSS)
13. “Her işlem ücretli. Mesela özel bölüm var, ikinci katta, ışıık gören bir yer. Kemoterapi alınan yerler bile farklı, SGK kapsamında tedavi alanlarla almayanların ilacı aldıkları oda bile farklı. 2. sınıf muamele var hastane içinde. Bodrum kat diyeyim size, B1 diye geçiyor, ışıık yok, suni ışııklandırma olan bir yerde alıyorsunuz siz kemoterapiyi ama özel bölümlerde, direkt ücreti olan yerlerde ya da özel sigortası olan kişilerin ilaçlarını aldığı odalar hastanenin çok daha lüks yerlerinde, daha konforlu.” (P7-GSS)
14. “Yani genel olarak tabii ki özel hastanede bir hizmeti almak çok daha kolay ve konforlu. Elbette imkanım olsa bir daha tedavi için herhalde devlete gitmem ama gitmek zorunda kalıyorum. Bazen mesela kan tahlillerimi hala devlette yaptırıyorum, işte iğneyi devlette oluyorum çünkü dediğim gibi özelde olmak sürdürülebilir değil. Hani bir kere iki kere verebilirim bu parayı ama ben bu iğneyi 3, 5 sene olacaksam her ay bu parayı veremem, bunun bir anlamı yok yani, o yüzden hala mekik dokumam devam ediyor.” (P1-GSS)

15. “180 lira [iğnenin uygulanması için ödediği ücret], işte bir de otoparka girip çıkıyorsunuz 200 lira diyelim. Her yıl da zamlanıyor bu. Evet yani, 1 yıl sonra onun yüzde kaç zamlanacağını bilmiyoruz. Ne isterlerse ödüyoruz. Ne derlerse kabul ediyoruz...” (P2-GSS)
16. “Dezavantajlardan da bahsediyorlar size, radyoterapi için söz konusuydu bu [ameliyat olduğu hastanede]. Alet yeni değilse yemek borusunda yanmalara neden olabilir, göğüs bölgesi zaten yeni dikişli bir bölge ve orada da yanmalar oluşabilir, ısı artışı yaralara sebep olabilir... Size canınızdan bahsedilince siz de otomatik olarak son teknoloji olsun da ben de bu acıları çekmeyeyim diyorsunuz ama ben böyle düşünemedim bu sefer 15 bin lirayı duyunca. Hiç vermek istemedim bu parayı ve kendi hastanemde [kemoterapi aldığı hastane] devam ettim radyoterapiye de. Bu arada aynı aletlerdi, kendi hastaneme döndüğümde sırf merakımdan aletin ismini ve kodunu sordum, birebir aynı aletti.” (P12-GSS)
17. “Gerçekten çok inanılmaz boyutta paralar ödeniyor ve benim gözlemlediğim kadarıyla kimse, hiçbir hasta bunun peşine düşmüyor çünkü insanlar... Dediğim gibi, o anda hasta psikolojisi devreye giriyor ve canların kurtarmaya çalışıyorlar. Paraları varsa veriyor insanlar, yoksa da veremiyor ve başka bir yerde [ameliyat] oluyor. Aslında çok ilginç bir psikoloji bu, bir yandan minnettar kalıyorsunuz bu insanlara. Evet, yapılmaması gereken bir şey [resmi olmayan ödemeler] ama bana bu konforu yaşattıkları için hastaneyi de doktorları da seviyorum diyebilirim. O kadar para döktüm diye düşünmüyorsunuz, çok değişik bir psikoloji bu.” (P6-GSS)
18. “Ben para ödüyorum. Bir kere doktorun muayene ücreti var, 3 ayda 1 ödediğim. Katkı payı olarak ödediğim ücretler var. Her kemoterapiden önce ödediğim bir kan testi ücreti ve gene kemoterapi ilaçlarına katkı olarak ödediğim bir ücret var. Kemoterapide kaldığınız saatin kısalığına ve uzunluğuna göre değişen bir ücret bu. Mesela diyelim ki 4 saat kemoterapi alıyorsunuz ve sizden 300 lira civarında bir para alıyorlar seans başına. Katkı payı diyorlar buna. Mesela diyelim yarım saat ile 1 saat arası bir tedavi alıyorsanız bu ücret 200 liraya düşüyor. Tam olarak neden böyle olduğunu bilmiyorum, sormadım da. MR için ve tomografi için yine katkı paylarını ödüyorum. PET için hiç ödemedim şimdiye kadar, tamamını devlet karşılıyor diyorlar. Genel olarak özel hastanelerde yapılan işlemlerde fark çıkıyor dedikleri için para ödüyorum.” (P11-GSS)
19. “Baştan neden söylemediniz yani, sonuçta herkes bütçesine göre bir yere gider. Baştan söyleseydiniz bunun benim bütçeme uymadığını bilir ve tedavimi burada almazdım. Baştan neden ücreti söylemiyorsunuz. Bizim şeyimiz böyle işte diyor, sistemimiz. O zaman da param yetmediğinde bitiminde buna hazırlıklı olacaksınız. Madem siz bana baştan ne ile karşılaşacağımı söylemiyorsunuz, siz de bitiminde benim paramın olup olmadığının riskini almış oluyorsunuz. Bana baştan deseniz ki bu 60 bin liralık bir tedavi, sizin sigorta limitiniz ne kadar onu biz bilemeyiz, ben de açar bakarım internetten, benim 15miş, 45 kaldı geriye, 8 bin lirasını da SGK ödesse bana 32 kalıyor, ben zaten arkama bakmadan kaçarım buradan!” (P9-GSS ve PHI)

20. “Mesela randevu alırken doktordan söylüyorlardı doktorumuzun muayene ücreti şu kadardır diye. Radyoterapi hakkında görüştüğüm zaman da şu kadar bir ödeme alacağız, şu zaman alacağız diye bilgi veriyorlardı ama hani bu süreçte ben tedaviye başlayacağım zaman önden bana böyle bir döküm sunmadılar, şurada şu kadar, burada bu kadar ödüyorsunuz gibi bir açıklama olmadı. Hep böyle sırası geldikçe, yeri geldikçe, gerek olursa, son dakika falan... Biraz böyle *step by step* ilerleyen bir bilgilendirme oldu. Bilgilendirilmedim diyemem ama ameliyat konusunda geç öğrendiğimiz için, bu arada ameliyatı da hemen kısa bir süre içerisinde yapmaları gerekiyordu, yani biz fiyat bilgisi aldık ve 2 hafta içinde ameliyat olmam gerekiyordu. 2 haftada 100 bin lira bulmam gerekiyordu yani. Bu geç bir bilgilendirme. Belki biz sormadık, üstüne düşmedik, belki onlar bilgilendirmedi de denilebilir ama hani hasta da o haldeyken, zaten kemoterapi alıyor...” (P6-GSS)
21. “Her şey mükemmeldi diyebilirim tek kelime ile. Sekreterinden tutun da radyoterapi teknisyenleri... Doktorlar zaten genç, pırıl pırıl, her şeye zamanında müdahale eden ve iyi tedavi sunan, güven veren doktorlar açıkçası. Hemşireler keza öyle. Hastaneler zaten tertemiz. Servis açısından hastaneye yatışından taburcu olmama kadar geçen süre, sonrasında medikal onkoloji ve radyoterapide geçen süredeki personelin yaklaşımı gerçekten kayda değerdi. Kanseri tedavisi konusunda bence epey ileri düzeyde bir hastane K (Anlaşmalı özel). Benim her türlü işlemim, kontrollerim, aylık tedavilerim için K'ya gidiyorum. Takip sürecinde belli aralıklarla randevu alabilme, doktora ulaşabilme anlamında, e-mail olsun, telefon olsun, hemen ulaşabileceğimin güvenini bana verdiler. Hem ameliyattan sonra hem de kemoterapiye başlamadan önce, -biliyorsunuz ağır bir tedavi bu-, hem beslenme hem de kemoterapi görece bölgenin bakımı ile ilgili ne yapmam gerektiğine dair bilgilendirmelerde bulundular. Tam anlamıyla dört dörtlüktü diyebilirim.” (P8-GSS ve PHI)
22. “Ben pozitif etkilendiğini düşünüyorum çünkü bir kere sürecin başından beri doktorlar sizin hastalığınızın muhteviyatına hakim oluyor. Doktorlar sürekli birbirleriyle iletişim halinde oluyor, cerrah tanıdığı onkoloğa yönlendiriyor, sürekli konuşuyorlar, plastik cerrah genel cerrahı arıyor ve benimle alakalı konuşuyor. Konseylerde bu hasta 6 ay önce böyleydi 3 ay sonra şöyle olacak, şu anda böyle diye bütün sürece hakim oluyorlar ve ben bunun avantajını gördüm diyebilirim. Doktorlar kendi aralarında işte, mesela onkolog diyor ki siz şu cerrahın hastasısınız, tamam, o zaman işte biraz daha ilgili ve farklı davranıyor falan. O açıdan ben olumlu bir etkisi olduğunu düşünüyorum tek bir yerden tedavi almanın. Bir de bence ilk gittiğin cerraha ameliyat olmak kesinlikle çok güven verici bir duygu, o yüzden ameliyatın hemen öncesinde değiştirmek istemedim hastaneyi. Eminim öbür cerrah da çok iyi yapardı ama tanımiyorum, bilmiyorum, gideceğim ve beni ameliyat et diyeceğim, güven duyuyorsunuz.” (P6-GSS)
23. “İsterdim tabii ki, maddi külfeti olmasaydı. Zaten ameliyat ve diğer tedavileri ayrı yerlerde alsan bile hala bir fanusun içine çekilmiş oluyorsun. Her şeyi orada yaptırmak istiyorsun. Onun dışına çıkmak istemiyorsun, hastane seni tanısin, sen hastaneyi tanı. Bir tuşla her şey hallolsun. Ben onlara bir şey

anlatmak zorunda kalmayayım. Öbür türlü düşünsenize ben bir şey için gideceğim dışarı, o parası için gideceğim başka bir yerde çektireceğim, onu getireceğim geri, sekretere vereceğim, tarayacak, tarayıp yükleyecek oraya, yani en ufak bir şey gözden kaçsa, bir şeyi tarayıp koymamış olsa doktor onu orada görmeyecek, ama öbür türlü ekrandan tuşlayıp her şeye bakabiliyorlar. Bu bana güvenilir geliyor.” (P2-GSS)

24. “Çok zor bir süreç bu, bir oradasınız, bir buradasınız. Bu arada asistanlar sizin dosyalarınızı unutuyorlar, asistanlar dosyaları unuttuğu için sürekli bir ona bir buna dosya yollayıp duruyorsunuz, bütün süreci aslında onkolog veya cerrah değil hasta olarak siz yönetiyorsunuz. Hangi hasta olduğunuzu, kim olduğunuzu her seferinde yeniden anlatmanız gerekiyor, o yüzden çok zorlu oluyor bu git-gel süreçleri.” (P12-GSS)

25. “Aynı hastanede tedavi almak benim bakış açımdan gerçekten her anlamda konforluydu çünkü çok yorgun oluyorsunuz, orada burada araştırarak, koşturacak, gidip gelecek haliniz olmuyor. Bizde bir de araç yoktu o sırada, çoğu arkadaşım kemoterapi almaya toplu taşıma ile gidiyordu, çok ciddi enfeksiyon kapıyorlardı kemoterapi döneminde. Dolayısıyla şansımızı zorladık biraz, taksiyle veya eş dosttan rica ederek gittik. Onun dışında aynı yerde olması bunların dışında doktorların sizi takip etmesini de kolaylaştırıyor. İletişim halinde oluyor tüm doktorlar, birlikte karar alıyorlar. Bu beni rahatlatmış ve daha güvende olmamı sağladı. En azından bunu dert etmedim. Aynı yerde olması [tedavinin] benim hem güvende hem de psikolojik olarak çok rahat olmamı sağladı.” (P10-GSS ve PHI)

26. Türkiye’de iyi işleyen bir şey var, benim çocuğum yok ama siz benim kızım olsaydınız muhtemelen o süreçte benle kalırdınız. Bu müessese yürüyor Türkiye’de. Anne-çocuk, kardeşler, yoksa da arkadaşlar, ama herkesin bir hayatı var, işlere gidiliyor, kimse hayatı erteleyip sizle ilgilenemiyor, biri gerekiyor bunun için, o biri de para demek, bu böyle.

... 58 yaşına kadar çalıştım ben ama emekli olmuştum, kocamdan ayrıldığım için çalışmak zorundaydım, çalışmayı da severim, dolayısıyla o süreçte hiç emekli maaşı almıyormuşum gibi bir bütçe yaptım. Çok kocaman olmayan fakat bu hastalıktan sonra kıymetini anladığım bir birikim oldu. Çok önemli bir kısmını bana yardıma gelen kadının maaşı olarak ödedim. (P4-GSS ve PHI)

27. “[Tedavisi tamamlandıktan sonraki süreçten bahsediyor] Bir de şöyle bir şey var, ben mesela bir gün omzum ağrıyor dediğimde doktor çok tedirgin olmuştu, yani böyle şeyler de var. Sonra doktorum bana şey dedi mesela, 'Sen bir yerim ağrıyor dediğinde ben oraya bakmak zorundayım'. Yani artık riskli bir hasta durumundasın göz ardı edemem bunu dedi. MR çekelim dedi. Neyse MR çekildi, yani 2 bin küsur lira sadece omuz MR'ı yani. Hani düşünüyorum benim bir ay sonra kontrollerim var mesela, bütün vücut taraması olacak, acaba ne kadar ödeyeceğim diye düşünüyorum yani.” (P2-GSS)

28. “...işimiz burada bitmiyor (tedavi bittiğinde). Peki ya sonrası? Testler? Görüntülemeler? Tedavi sonrası da oldukça sıkıntılı oluyor, bununla ilgili bir

soru var mı bilmiyorum, hiç duymadım. Tedaviden bahsediyorlar. Tedavi bitti! Ben ne yapacağım? Doktor 3 ayda bir PET, tetkikler, mamografi, ultrason, jinekolojik muayene ister... Bunlar? Bunlar ücretlidir. Hasta yine aynı hasta! Peki tedavi bittiğinde bu hasta grip olmuş gibi iyileşti mi? Bu hastalığın bir de bu aşaması var ve bu da garanti altına alınmalı, hasta bunun stresini yaşamamalı. Bu nasıl çalışacak? İlaç paramı ödemiyo, nereden bulabilirim? Dava açmalı mıyım? Bu işin acı tarafı bu. ... Tedavi sonrası kontroller de çok önemli.” (P10-GSS ve PHI)

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