

EXPERIENCING AND EXPLAINING CANCER: A CRITICAL STUDY  
OF TURKISH MODERNITY THROUGH THE CANCER PATIENTS'  
ILLNESS NARRATIVES

by

AYSECAN TERZIOGLU

A dissertation submitted to the Graduate Faculty in Anthropology in partial  
fulfillment of the requirements for the degree of Doctor of Philosophy,  
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## **Abstract**

# **EXPERIENCING AND EXPLAINING CANCER: A CRITICAL STUDY OF TURKISH MODERNITY THROUGH THE CANCER PATIENTS' ILLNESS NARRATIVES**

**by**

**Ayşecan Terzioğlu**

Adviser: Professor Shirley Lindenbaum

Based on 12 months of fieldwork in İstanbul and Ankara, my dissertation aims at providing a critical reading of Turkish modernity and its reflection in the health realm through an investigation of the illness narratives of cancer patients. It also explores the interactions between the medical and social conceptions of cancer in Turkey, and the ways in which the illness narratives are informed by those conceptions. Analysis of narratives suggests that the patients internalize, reshape or react against the larger, social and medical conceptions in their illness narratives, in accord with their own experiences during their cancer treatment. The patients' socio-economic background and position vis-à-vis Turkish modernity play a crucial role in shaping illness experiences and narratives. The recent social transformation in Turkey and criticisms of Turkish modernity are reflected in the health realm, particularly in terms of the health care providers' categorizations of "good" and "bad" patients, which are informed by the providers' perceptions of the patients' socio-economic status.

The fieldwork includes interviews with 20 female breast cancer patients, 20 male lung cancer patients, and five men and five women with cancer in their digestive systems. Analysis of their cancer narratives evaluates the extent to which the patients experience marginalizing and discriminatory practices by health care providers and other people who are around them. By constructing illness narratives, the patients often re-arrange their social world and reconstitute

their self-image in order to cope with those practices, as well as with the physical and psychological problems that are caused by their illness. They often form a small group, which includes the people who support them during their treatment in psychological and material terms, and reinforce the boundaries between that small group and the “others” in sharing their illness experience and narrative. The health scientists and health care providers focus more on why the cancer rates have increased, rather than on how having cancer affects people and what kind of psychological, social and economic problems it brings to their lives. Therefore, the issues of how patients cope with those problems are underestimated in the debates on cancer in Turkey.

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## **Introduction**

In my dissertation I aim at providing a critical reading of Turkish modernity and its reflection in the health realm through an investigation of the illness narratives of cancer patients. I also explore the interactions between the medical and social conceptions of cancer in Turkey, and the ways in which the illness narratives are informed by those conceptions. The medical conception of cancer differs highly from the popular conceptions of that illness, especially in terms of what causes it and its association with death, despite the health care providers' efforts to propagate their medical views. The patients internalize, reshape or react against the larger, social and medical conceptions in their illness narratives, in accord with their own experiences during their cancer treatment. My research indicates that the patients' socio-economic background and position vis-à-vis Turkish modernity also play a crucial role in shaping illness experiences and narratives. I contend that the recent social transformation in Turkey and criticisms of Turkish modernity are reflected in the health realm, particularly in terms of the health care providers' categorizations of "good" and "bad" patients, which are informed by the providers' perceptions of the patients' socio-economic status. Those categorizations influence the health care providers' attitude towards the patients, and the patients feel discriminated both in economic and social terms.

Analysis of the cancer narratives evaluates the extent to which the patients experience marginalizing and discriminatory practices of health care providers and other people who are around them. By constructing illness narratives, the patients often re-arrange their social world and reconstitute their self-image in order to cope with those practices, as well as with the physical and psychological problems that are caused by their illness. I examine how constructing these narratives helps the patients to give meaning to their own illness

experience and to cope with the dramatic changes that cancer has brought to their lives. The illness narrative is a powerful tool for ill people to reflect upon and reconstruct their identity and social position in order to re-establish a culture-specific sense of order and continuity after the disruption (Mattingly, 2000). I also investigate how the cancer patients combine public and private realms, common and intimate knowledge, and history and biography in their illness narratives in their struggle against marginalization, stigmatization and discrimination in their everyday life and during treatment. The cancer narratives often include the most public and private aspects of the patients' illness experience and life in general, which allows me to analyze how the patients situate themselves in the medical realm and within their society. I collected cancer narratives by interviewing fifty cancer patients, and I also benefited from the written illness narratives of some public figures who had cancer. I conducted my research in Güvercin hospital, which is a small and private oncology clinic, and in the oncology clinic of the SSK hospital, which is a major state hospital.

**The Recent Social Changes and Critique of Turkish Modernity:** Growing up in the 1980s and witnessing the social transformation in Turkey at that time have influenced my academic perspective, as well as my research and study interests. I have been influenced by those social changes both at a personal and intellectual level, and they constitute the starting point of my journey in the academic life. My further studies in sociology and anthropology, and the research projects that I was involved in, led me to gather the pieces of puzzle along the way. Since the 1980s, significant social and political developments have taken place in Turkey, such as rapid urbanization and industrialization, the massive flow of migration from the rural areas to the main cities, and the rise of political Islam. As a result, Turkish modernity, which is often embodied in the ideology of Kemalism, is questioned by scholars

who argue that the unitarian aspect of that ideology fails to reflect the social and cultural diversity in Turkey. The word Kemalism, which can be loosely defined as the Turkish modernist principles that were advocated by the founder of the Turkish Republic, Mustafa Kemal Atatürk, was coined after his death in 1938. There is no single definition of it, and politicians and intellectuals have easily manipulated its meaning according to their own political views and agendas. However, the common points in different versions of Kemalism are its emphasis on secularism, rationality and scientific thinking. Kemalism also includes the aim that Turkey should develop and compete with the modern, Western civilizations in political, economic, scientific and technological terms.

As a result of the recent social changes the elites have become more heterogeneous in terms of their social background and political opinions. The new elites also joined the scholars and intellectuals in their criticisms of Kemalist ideology and its exclusionary policies against “non-modern” citizens (Keyder, 1999). Thanks to the new pluralism in society, dramatic debates about Turkish modernity in terms of how it shapes Turkish identity and citizenship have dominated the public sphere in Turkey. Multiple voices are heard in those debates, partly because of the shrinking political and economic power of the state. Ethnic and religious groups, such as Kurds and Alevites, have raised their voices against their social and political marginalization by Turkish modernity, which tends to favor Sunni Turks in defining citizenship rights. Those recent criticisms and the new social pluralism have caused a rupture in the conception of Turkish modernity, and allowed the formation of multiple modernities both in terms of life styles and ways of thinking (Knauff, 2002). However, the old elite, who still distinguish themselves from the new elite and other people through their adherence to Kemalism, argued against the multiple modernities and their manifestations in every day life. They claimed that those

are dangerous deviations from the true path of modernization, which can lead Turkey back to the “dark ages” of Ottoman rule, or worse, transform Turkey to become the next Iran or Malaysia<sup>1</sup>.

Feeling threatened by the multiple modernities, the aim of the Kemalist elite to modernize society is largely replaced by their efforts to reinforce the social and cultural boundaries between them and the “others.” In defining their social status and identity, the Kemalist elite emphasized their Western-style education and “orientation toward an urban, secular, Western life style” as opposed to the rural, provincial or religious lifestyle or the views (Kasaba, 1997; Arat, 2001; White, 2002). The efforts to reinforce the boundaries and maintain the Kemalist vision of Turkish modernity led the old elite to form Kemalist organizations, hold demonstrations against Islamism, hang Turkish flags from houses, and avoid “Islamist” neighborhoods and people. Despite the fact that AKP (*Adalet ve Kalkınma Partisi*, Justice and Development Party), which is the party in power in Turkey today, is considered “Islamist” by the old elite, Kemalism is still the official ideology of the state and its main institutions. Kemalism is also regularly promoted through the mainstream media and in primary and high school education in order to raise new Kemalist generations. The Turkish military, which played a pivotal role in the foundation of Turkish republic, by winning the “War of Independence” against the allied forces, which invaded most of the country after the First World War, is also closely associated with Atatürk, who is its perpetual “chief commander.” The military also acts as the guarantor of Kemalist ideology, and it often intervenes in political affairs in times of “crisis” when this ideology is “in danger.”

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<sup>1</sup> Since the 1990s, the Kemalist scholars and journalists often express their concerns that Turkey will be similar to Iran or Malaysia, since they believe that AKP will eventually implement and impose laws, which will threaten the secular political and social life in Turkey.

The old elite, whose views are supported by the state discourse, mainstream media, educational institutions and military still have the political and social power to impose their own version of modernity over alternative visions and conceptions. This power also helps the elites to maintain their social status and self image, as the people who are responsible for Turkey to develop and modernize, and as a consequence, to produce or reproduce the social inequalities that are based on the definition of who is modern or not. The clash between the Kemalist elites and “others” has shaped not only the political debates in the public sphere, but also the day-to-day social and cultural interactions since the 1980s. I became aware of that clash and had a chance to observe the ways in which it manifests itself in everyday life during the 1990s, when I studied sociology in the university, together with the students who differed from each other in terms of their socio-economic background, life style and political views. I noticed that this clash was gradually changing society, both by leading people to be more vocal about which social group they belong to, and by creating a platform where different people could discuss conceptions of modernity other than Kemalism, which has been regularly imposed on several generations since the 1920s. The social transformation is also reflected in the medical realm, which is considered as “one of the last bastions” of Kemalism by many Turkish health care providers.

After being involved in a research project in 1994, where I conducted interviews and participant observations in a university hospital in İstanbul, I decided to study the recent social transformation in Turkey through an investigation of issues of health and illness, which also have important political, social and cultural aspects. During this first research project, where I worked in a university hospital, I noticed that the clash between the modernist elites and the “others” was reflected in the medical realm in a particular

way, and played an important role in shaping the interactions between patients and doctors, especially in the state hospitals. The close association between modern medicine and Turkish modernity, which dates back to the introduction of modern medicine in the early 19<sup>th</sup> century, is related to the pivotal role that the doctors played in the Turkish modernization process.

**Turkish Modernity and the Medical Realm:** In my master's thesis, I investigated the interaction between Turkish modernity and medicine from the 19<sup>th</sup> century to 1990s, with a focus on different generations of doctors' professional experiences and narratives (Terzioğlu, 1998). The introduction of modern, Western medicine, which included the foundation of medical schools and hospitals under the guidance of European doctors in the Ottoman Empire, was one of the earliest and most important processes of Turkish modernization. Most of the earlier generation of doctors had an urban and elite background, since they came from families who could afford to send their children for seven years of university education. Until the late 19<sup>th</sup> century, the language of instruction was primarily French and German, which facilitated the doctors' role in the modernization process because of their easy access to Western languages, sciences and cultural knowledge. Like Atatürk, they believed that Turkish society should be modernized by adopting modern, Western scientific and technological developments, as well as the European political system and social institutions. Therefore, they internalized the task of solving not only the medical, but also the social problems of the population (Gürsoy, 1996; Dole, 2005). In the 1980s, that task was partly replaced by more professional and individual concerns among later generations of doctors, because of the recent heterogeneity in the socio-economic status of doctors and privatization in medicine. However, there are still a large number of doctors who believe that

they should play an active role in the modernization of society by imposing their medical and scientific conceptions of health and illnesses, and by fighting “superstitious” beliefs often informed by the popular interpretations of Islam. Most doctors expect full obedience and respect from patients for the treatment to be effective, because doctors see themselves as having the most accurate, science-based knowledge.

The doctors’ association with modernity and doctor-patient interactions are also influenced by the process of privatization in medicine, which started in the early 1990s, and increased inequalities in access to health care services (Sanal, 2004). Besides the inequalities in the distribution of health care institutions between the urban and rural areas, the economic inequalities affected access to health care. Patients who can afford private insurance or pay high service fees, now receive care in private hospitals, which provide longer examination periods, better interactions with health care providers, and fewer bureaucratic issues than they receive in state hospitals. Along with privatization, the state budget for health care services also dropped considerably, especially for the state hospitals in the major cities such as İstanbul, and was inadequate for providing services to the rapidly increasing urban population. As a result, the waiting rooms of state hospitals became increasingly crowded, with long lines at the front desks, and patients who wait for months even for urgent operations. The state insurance system is also affected by the recent economic problems and increasing urban population, and it is increasingly associated with corruption and tedious bureaucratic arrangements for the patients. Moreover, the patients’ complaints about the tense and aggressive attitude of health care providers became a public issue, which is often represented in the media. The patients often emphasized that they are human beings who deserve the health care providers’ respect and care, instead of being treated as “ignorant villagers.” In response to such complaints, the health care providers said that they treated dozens of

patients each day and that their working hours were much longer than their colleagues in the private hospitals. The doctors working in İstanbul's public hospitals often complained that many patients did not even speak Turkish<sup>2</sup>, seemed to come from the village "just yesterday," and did not know how to behave in the hospital and interact with doctors. In contrast, many private hospitals claim that they provide "five star hotel" quality for the patients. However, private hospital treatment is much more expensive, and only 5% of Turkish cancer patients can afford it (Ministry of Health, 2002). The differentiation between the private and public hospitals has also added to the tension and increased the gap between the doctors most of whom closely associated themselves with the Turkish modernization, and their patients who are left out of the modernization process.

**Turkish Modernity and Cancer Narratives:** In my Ph. D. studies, I became more acquainted with the literature of the anthropology of health and illness, and I decided to investigate the social problems in the Turkish medicine through the patients' perspective. I also became interested in how the patients evaluate and deal with the psychological and physical problems that their illness causes. How do the patients reshape their social identity and interactions in accord with their illness experience? How do the illness narratives reflect those processes? In constructing their illness narratives, the patients combine their views on the medical and social conceptions of their illnesses with their evaluations of their illness experiences, which include their interactions with health care providers and their positive views of alternative or complementary medical practices. Those topics included in the illness

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<sup>2</sup> The massive migration from the rural areas to the major cities in the 1990s included a large number of Kurds, who did not join the Kurdish separatists and fled from the civil war in the South Eastern Turkey. Therefore, most of them only spoke Kurdish and its various dialects, and did not learn Turkish, even after migrating to the cities.

narratives led me to focus on how the patients position themselves vis-à-vis the Turkish modernist ideology and practices, and how that position influences their illness experiences. The illness narratives reflect the patients' efforts to give meaning to what they experience, and indicate the complexity of the illness experience better than surveys or statistical analyses.

In order to study this topic, I chose cancer, which has affected many patients and has a high visibility in Turkish society. Cancer is also related to various public issues and debates, as well as the private and personal ones, such as sexuality, self-image and identity. Studying cancer patients' narratives also allowed me to investigate the inequalities and discrimination in the health realm in both personal and social terms. Cancer, which often requires long-term medical treatment and affects the patients both psychologically and physically, is highly suitable for investigating these issues. Cancer is also the most commonly discussed illness in Turkey today, and it has become an iconic illness that is associated with the recent social transformations, political debates, and environmental problems. Both cancer rates and rates of mortality due to cancer have increased dramatically since the 1980s, inducing panic and anxiety in the society and among the health scientists. Cancer has become the second most prevalent cause of death in Turkey after heart diseases, and its popular association with death is acute, despite the recent developments in cancer treatment (Ministry of Health, 2002). The medical and social conceptions of cancer are often in conflict with each other, especially when people discuss the main causes of increasing cancer rates and the efficacy of medical treatment and alternative or complementary treatment methods. That conflict is also reflected in the interactions between doctors and cancer patients and the increasing tension and mutual mistrust between them.

The cancer patients evaluate those conceptions and combine them with their own illness experience. The patients often develop a dualistic discourse on modern science and

medicine, which includes both a reverence for the medicine's efficacy in diagnosing and treating their cancer, and a reluctance to visit hospitals, due to the problems they experience in their interactions with health care providers and in dealing with bureaucratic issues. The dualistic discourse is informed by the patients' rather abstract and idealized conception of modern sciences and medicine, and their often-problematic personal experiences in the medical institutions. A similar dualism is also present in the patients' position vis-à-vis Turkish modernity, and which principles that they should prioritize. Most patients praise the state's modernization efforts to achieve the level of the richest and most powerful, Western countries, and they argue that people should cooperate with those efforts. However, they also emphasize that Turkish society should maintain its "good characteristics," such as the importance of family ties and communal solidarity. Several patients also stressed that Turkish modernity should not exclude the religious way of life and thinking from the public realm, since they also consider religiosity to be a good characteristic which leads people to help each other and be virtuous. Those characteristics are described in an idealized way and thought to be inherent in Turkish society, independent of the variations in people's socio-economic background. They are also considered to be the traditional characteristics, since they shaped the society "for centuries." The patients admitted that it is, therefore, very hard to change them, despite the rapid modernization and globalization. Those characteristics are often contrasted with the characteristics of the "Western societies," which are described in the same generalized way. Accordingly, several patients described "Westerners" as cold, materialist and selfish, and argued that many Turkish doctors are also becoming like them, as their scientific knowledge and education distances them from their own people. Those descriptions also keep the patients hopeful, by reminding them there will always be a few

people who will understand their problems and help them in solving those problems because of the “good characteristics” of Turkish people.

Starting with the first examinations and tests, which lead to the diagnosis of their cancer, the patients form strategies about when, how, and with whom to share what they experience, and this helps them to have a certain degree of control over the effects of their illness, especially in their social lives. Most patients distinguish the people “who really care for them” and “who can help them,” from the “others” who fail to empathize with them and their physical and psychological problems. The former mostly consisted of a small group of close relatives, neighbors or friends, who accompany the patients in their hospital visits and who share every aspect of their illness experience. Despite most patients’ stress on the typical Turkish characteristics of helping each other and giving priority to the family ties, my research indicates that elderly patients with a low socio-economic background, especially the female ones, experience difficulties in sharing their illness experience with their family members and friends. These patients explain that some people once close to them gradually became estranged after their diagnosis. On the other hand, they also cite “more excusable” difficulties, such as the people who are close but who cannot take a day off from work to accompany them to the hospital, or who have their own health problems, which are “as serious as cancer.” When the cancer patients are not accompanied to the hospitals and they stay there for several days with the other cancer patients in the same ward, those patients “become the family members” for each other, and share their problems on a regular basis during their treatment.

The need for such a small “support group” is essential, since most of them do not have access to professional psychological support, or they are reluctant to accept such support within the hospital context. The patients rarely share their psychological problems with the

health care providers, except with the few doctors and nurses in the private hospital and during a long-term treatment, since the health care providers prioritize the patients' physical problems during their brief examination. The doctors in state hospitals argue that they cannot afford to listen to the patients' psychological problems because of the crowd and the lack of professional psychological support in most state hospitals. However, except for two patients, most cancer patients I interviewed said that they do not need professional psychological support<sup>3</sup>. Moreover, the doctors' regular advice to the patients to keep their morale high and be strong, and the patients' concerns about not upsetting the people who are close to them, prevent them from expressing their complaints about their illness experiences and the bodily changes that their illness and treatment cause. The bodily changes range from the minor ones, such as nausea and fatigue, which affect the patients' everyday lives, to loss of hair or an organ, which affects the patients' self-image, social interactions and sexuality. The latter affect the patients' lives drastically, and it is difficult for the patients to cope with those changes in emotional terms. Like the other aspects of their illness experiences, the patients choose whom to share their experiences with, and they and re-arrange their private and public aspects of their illness accordingly.

**Methodology:** I collected most of my research data for my dissertation in İstanbul and Ankara during one year of fieldwork, from June 2003-July 2004. I also continued to collect the published material for my thesis until 2007, considering the ongoing debates on cancer in the Turkish media and the increasing number of the books

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<sup>3</sup> Having psychological counseling is generally associated with having a major psychological disorder in the Turkish society, except for the few urban, middle or upper class people. On the other hand, participating to a group therapy became more common since the early 1990s, especially for the cancer patients (Serbest, 2004).

on the cancer experiences of public figures. My research thus consists of two parts, which complement each other. Collecting illness narratives through interviews however is the main method. My interviews were semi-structured, since I wanted the patients relate their life and thoughts about the illness experiences and treatment which they considered important, rather than limiting them to my own questions. Most interviews lasted for periods that varied from forty minutes to three hours. I interviewed a total of fifty people with cancer at SSK, which is a state hospital, and Güvercin, which is a private hospital, in İstanbul.

I chose İstanbul as a research site because it is the economic and cultural capital of Turkey, and it is also the most heterogeneous city in social, cultural and economic terms, since it has received a flow of migrants from various places both in the Ottoman Empire and Turkey. That heterogeneity makes the city a major arena for the current debates about the “essentialized oppositions of East and West, global and local, modern vs. Traditional, Islamic vs. secular life-styles” (Keyder, 1999). İstanbul experienced the recent social transformations more vividly than the other Turkish cities. It also has the highest number of migrants from Anatolia. The flow of migrants often causes political and social tension between the “new comers” and the “old residents” who resist the ways in which the “new comers” change the social and cultural life in the city. The old elite and their successors who are attempting to transform the city into a global capital can hardly cope with the changes brought by the recent migrants from the rural areas in Anatolia in terms of the city’s social, cultural and economic life. This is most visible in different kinds of clothing, food, and ways of socializing. That intolerance has increased the debates about who owns İstanbul in terms having a right to its past and present, and it

has manifested itself often in everyday life in the social institutions where people with different socio-economic background come together (Keyder, 1999; Bartu, 1999).

In choosing the hospitals, my criteria were to select two hospitals which differ considerably in terms of the socio-economic background of the patients. I chose SSK hospital at Okmeydanı, which is a large state hospital that mainly serves the people with the SSK insurance, and the Güvercin hospital, which is a small, private one. The health insurance system in Turkey is based on hierarchical divisions according to the occupation of the “male householder,” and suggests that women and children may benefit from the same insurance through their husbands and fathers. Accordingly, the SSK insurance-holders are the “workers” for the state, most of whom work in jobs which require a low level of education and skills, and their close family members<sup>4</sup>. SSK hospital is also often visited by the people who do not have any health insurance because of its low fees, which corresponds to the 30% of the whole population, according to the 2003 World Bank report (Keyder et al., 2007). The patients who attend those two hospitals reflect the socio-cultural diversity in İstanbul.

In order to capture the historical changes in the conceptions of cancer, the people I interviewed belong to the last two generations, which also helped me analyze how the patients’ age influences their illness experiences and narratives. After investigating the cancer statistics on the patients’ age groups, I defined the younger generation’s age range as 25-55 and the elderly one as 56-75. Considering the higher rates of cancer in the latter group, both in Turkey and in two the hospitals, I interviewed 35 patients who

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<sup>4</sup> The other divisions in the Turkish health insurance system is *Emekli Sandığı*, which is for the state employees with higher professional rank, *Bağkur* for the people who have their own business, which also includes most farmers, and the *Yeşil Kart* (Green Card) holders, who prove their poverty through official documents. Scholars often criticize this system as being inefficient and corrupted, and they emphasize that a new and better coordinated insurance system, which is based on the concept of health as a universal, citizenship right, should replace the existing one (Keyder et al., 2007).

belonged to age group of 56-75, and 15 patients whose age range is 25-55. I also interviewed people in different stages of their illness and included people whose cancer is cured. I also took account of the particular ethnic, religious and regional background of the participants as well as their gender in evaluating their illness narratives. I chose to interview twenty women with breast cancer and twenty men with lung cancer, since these are the most common forms of cancer in Turkey. However, I also interviewed ten people, five women and five men, with cancer in their digestive system, such as the colon and stomach cancers, since they are also becoming common forms of cancer. I changed the names of the patients I interviewed in my dissertation in order to protect their privacy.

I conducted the interviews in the waiting rooms of the clinics, in coffee shops near the hospitals, or in the patient's houses in accord with the patients' preference. With the permission of the patients, I tape recorded and transcribed all the interviews, and wrote brief reports on each of them, which summarized the patients' account. Most patients were willing to talk about their illness experiences, and they said that talking with me comforted them, even though they do not know me that well, since they needed to share the problems that they were experiencing. A few patients and their relatives initially thought that I was a journalist, representing a newspaper or a TV channel, despite the fact that I insisted that I had nothing to do with the media, and talked about my affiliations with the CUNY-Graduate Center and Boğaziçi University. The increased visibility of cancer and cancer patients in the Turkish media led them to have those doubts, which led them to talk with me rather too self-consciously or reluctantly at the beginning of our interviews. Therefore I paid a special attention not to ask the

questions that the journalists often asked or to use the typical words that are used in media in referring to those patients, such as “surviving the war against cancer.”

I first elicited the life stories of participants in order to contextualize their illness narratives and asked about where they were born and raised, the schools they went to, their job(s) and family members. Then I asked questions about their health condition in general, focusing on whether they had any major health problem other than cancer, and what type of treatment they sought for that problem. When I moved on to questions about their cancer, I asked about the initial symptoms and what among those symptoms made them visit a doctor, and who or what else was influential in that decision. My questions also included possible reasons for their illness, their treatment process, their interaction with the health care providers and any complementary or alternative treatment methods. I inquired about the physical and psychological problems, as well as the changes in their social interactions, self-image, conceptions of life, death, body, health and illness and how they came to terms with those changes during their cancer treatment and afterwards.

In order to be able to contextualize the illness narratives and to understand the illness experiences in general, I spent 40 days in the examination and waiting rooms of both Güvercin and SSK hospitals. I observed the examination process and had informal talks with patients and health care providers about cancer and cancer treatment. My observations also allowed me to become more familiar with the medical and popular discourses on cancer and cancer patients, and to investigate how people with cancer shape their illness narratives in their interactions with the health care providers. I also had the chance to observe the bureaucratic and economic problems that many patients endure during their treatment, as well as the tension and aggressiveness between the

patients and health care providers, which shape the social environment at SSK hospital to a considerable extent.

The second component of my study is the investigation of official, popular and medical discourses on cancer and how those discourses have changed since the 1930s, in order to contextualize my analysis of my interviews further. I explored how cancer and cancer patients are commonly represented in those discourses, by conducting a media survey and collecting books, brochures and reports. I also collected the autobiographical books written by Turkish public figures such as journalists, movie artists, writers and academics with cancer, and which cover their illness experiences. The writers often include how they react to their cancer diagnosis, different stages of their treatment, and how they are affected by their treatment. They also give practical and general advice for cancer patients on how to cope with their illness and how to alter their daily life in order for their treatment to be more effective. Those public figures often present themselves as role models for other cancer patients, by emphasizing that they remained strong and kept their morale high despite their health problems, in accord with their doctors' suggestions. However, they do not deny that they come from a privileged socio-economic background and received much more moral support than the average patients. They often consider themselves lucky compared to the other patients who were more viewed as a cancer patient rather than as a human being by the health care providers.

In the media survey, I collected articles on cancer and cancer patients from six commonly read newspapers and three popular magazines. I also watched four Turkish popular TV series and three movies, in which one of the main characters had cancer. Both in the written and visual media, having cancer is closely associated with recent social and economic transformations in Turkish society, such as the rapid and

unregulated urbanization and industrialization processes. The media gives more voice to the doctors and health scientists as the “experts” on cancer, and only in the recent years has it included more patients’ perspective and voices. The experts often outline the differences between the “good” and “bad” patients with respect to their cooperation with the medical discourse and practices, and recommend avoidance of complementary or alternative treatment methods, which they consider do not have a scientific basis. For further contextualization, I collected the statistics on cancer and cancer patients in Turkey, and talked with the health scientists who interpreted those statistics in their research. Except for the media survey, I conducted most of the second component of my research in Ankara, which is the capital of Turkey. I visited the State Institute of Statistics, Ministry of Health, National Library and Hacettepe University, Department of Public Health, which specializes in research on cancer.

**Chapters:** In the first chapter, I describe the larger social and political context shaping the cancer patients’ illness experiences, with a focus on the recent social transformations in Turkish society and medical realm. I also discuss how the scholars, intellectuals and politicians have criticized Turkish modernization and its exclusive practices, and how the doctors’ close association with the modernization has changed since the 1980s. I describe the “medical neighborhoods,” in which those hospitals are situated, and explain how the social and economic life has changed considerably in those neighborhoods since the late 1980s. I also depict the basic structure and characteristics of the SSK (state) and Güvercin (private) hospitals where I conducted fieldwork. Finally, I discuss the illness experiences of two cancer patients, which are typical in terms of representing the doctors’ categories of “good” and “bad” patients.

Those two patients differ from each other in terms of their socio-economic background and position vis-à-vis Turkish modernity, and that difference shapes their illness experiences and their interactions with the health care providers to a large extent.

The second chapter is the literature review, which discusses the works of social scientists who focus on how the social and economic inequalities influence the patients' illness experiences and how patients respond to those inequalities. The inequalities in the health realm, especially in terms of access to adequate health care and enjoying more open, less hierarchical interactions with health care providers, inform the patients' evaluation of their treatment and conception of their illness. Those inequalities operate both at macro and micro levels, since they stem from the problems in the Turkish health system and they are manifested in the everyday interactions between the patients and health care providers. I discuss the works of social scientists who relate the inequalities in biomedical discourse and practices in different historical contexts. There are two approaches which investigate how the biomedical discourse and practices maintain and reproduce cultural, political and economic inequalities. The first is a discursive-interpretive approach, which focuses on the medical, social and cultural conception of illnesses, and investigates what it means to be ill in a particular social context. Scholars, who subscribe to this perspective, also study how the patients cope with anxiety, uncertainty, isolation and stigmatization brought by their illness. The second approach is provided by scholars with a political-economy focus on how the biomedical discourse and practices produce and reproduce political and economic inequalities at local, national and global levels. More recent studies argue that these two approaches should be combined in order to reflect the complexity of the issues of inequalities in the health realm more accurately. In accord with that argument, I also combine these two

approaches, in order to study how cancer patients' illness experiences are informed by the cultural, political and economic inequalities and discriminations. In addition, I review the recent social science literature on the health and illness issues in the Middle East, and in Turkey in particular, with a focus on how they combine those two approaches.

The third chapter covers the social and medical conceptions of cancer in Turkey, and relates them to the conceptions of other major illnesses in Turkey since the late 19<sup>th</sup> century. I discuss how the interactions among health care providers, health scientists, politicians and lay people shape the public policies and inform the common cultural associations with cancer. I analyze the discourse and practices of health care policies and medical organizations, which aim at preventing and curing cancer, as well as informing the people about the illness that often takes place by imposing the medical discourse and its war metaphors. I investigate why cancer has gained more social visibility since the 1990s, and relate this to the debates on the increase in cancer rates and its possible causes, among health scientists and health care providers, lay people, journalists, activists and politicians. I also cover the debate on whether the recent increase in cancer rates is a result of the nuclear disaster in Chernobyl and its effects on Turkey, and point out the political, economic, social and cultural aspects of different opinions on this debate.

The fourth chapter includes an ethnographic analysis of the social and physical environment at SSK and Güvercin hospitals, and the first two of the five main themes that commonly appear in the cancer patients' illness narratives. Those two themes are the patients' earlier responses to the cancer diagnosis and the changes in their personal interactions after the diagnosis, and they correspond to the patients' evaluations of the

initial part of their cancer treatment. I argue that the patients see the diagnosis of their cancer as a turning point in their life in terms of both their health condition and everyday interactions. Although most patients feel shocked after learning the diagnosis, some of them also said that they predicted the diagnosis, depending on their previous health records, experiences in hospitals and perceptions of risk. The patients' initial responses to living with cancer also vary from mobilizing all the available resources in order to learn more about cancer and paying attention to every detail about cancer treatment, to living as if they do not have cancer. The patients and health care providers often use the word "denial" with respect to coping with the idea of having cancer. However the patients give a more positive connotation, in the sense that they attempt to avoid letting cancer affect their social life and psychological well-being. There are also different ways of denying the fact that they have cancer, and both cite various reasons for that denial. In terms of the patients' personal interactions, most patients single out the role of their family in taking care of them, especially in the case of elderly, female patients who believe that they devoted their lives to their children who now have to take care of them. On the other hand, several women related their affliction to the ways in which they challenged the "traditional roles," such as prioritizing the family ties and reproduction, or by choosing a professional career, an attitude generally attributed by the society to them.

The fifth chapter covers the three other main themes in the oral and written cancer narratives: The attitudes towards urban and rural life; views on modernity, science, religion and education; and discussions about global and Turkish politics. The patients mostly refer to those themes as a part of their evaluation of their cancer treatment, and emphasized that those are important issues not only for themselves as cancer patients, but also for the whole of Turkish society and the state. I analyze how the cancer patients

conceptualize those issues in relation to their experiences during treatment. Those issues help the patients to build a bridge between their individual experiences and public issues, since they help them to give meaning to their treatment and to connect this personal meaning to more general public issues. The themes are interrelated and they often overlap both in terms of the patients' categorizations of good and bad patients or citizens. How the patients view the alternative or complementary medical methods and whether or not they benefit from those methods are also connected with those themes in various ways. The investigation of main themes in the illness narratives also indicates how the social and political problems in Turkish modernization are reflected and reproduced in the hospitals.

The chapters six, seven and eight deal with the personal and private aspects of illness experiences. The first two include the bodily changes cancer patients experience before (as symptoms), during, and after their cancer treatment. The Chapter six is about the patients' accounts of relatively minor problems, such pain and aches, tiredness and lack of energy, nausea and weight issues, and how they affect their self-image, everyday life and social interactions. I investigate how the patients establish a hierarchy among their bodily changes, with respect to which of them matters more. The importance of bodily changes is related to how they affect the patients' lives, and their urgency in terms of notifying a doctor before the diagnosis or afterwards. The patients decide about whether to share those changes with the health care providers, people who are close to the patients, and with "other" people. The fact that these minor conditions are less visible makes it difficult for the patients to talk about them with the "other" people and health care providers, although they may affect the patients' lives to a large extent. Therefore, dealing with less visible bodily changes may constitute the most personal aspects of

dealing with the changes that are brought by cancer and cancer treatment. They are also informed by the medical and cultural conceptions of illness and sick bodies, such as “bad water” that accumulates in the body.

The chapter seven discusses how the patients speak about the major bodily changes, such as their loss of hair and breast removal, which affect not only their body, but also their self image and social interactions. Those changes also have a powerful effect on their identity and sexuality on a long term or permanent basis. Although the patients’ hair grows again after chemotherapy and becomes even thicker and fuller, and some patients are able to afford breast reconstruction, the effects of these bodily changes go beyond the process of cancer treatment. The narratives on the major bodily changes lead some patients to re-organize their public and private lives and re-establish the boundary between those two realms. The major bodily changes affect the looks of people with cancer and single them out to a large extent in the public and private realms. They are also traumatic in the sense that they underline the difference between them and healthy people, both for the other people and the patients themselves. In response, the patients develop strategies about whether to hide or emphasize those bodily changes in different social environments and in their private lives. Those bodily changes are directly associated with having cancer and being unhealthy in general, even after the cancer treatment is over.

The last chapter discusses how the cancer patients face the idea of death and the fact that they may die sooner than they thought because of their illness. The social and medical conceptions of cancer, the patients’ socio-economic background, health condition, illness experience, age and religious views inform the patients’ reaction to the idea of dying of cancer and how that idea changed themselves and their lives. Cancer is still

commonly associated with death in Turkish society, and the cancer patients' narratives include different responses to that association. SSK and Güvercin hospitals also have strict policies about not using the words "death" and "cancer" unless "it is hundred percent necessary," which also furthers the taboo around those words. Those policies are related to the fact that health care providers explain deaths due to cancer with their personal failure, as well as with "irresponsible behaviors" of "problematic" patients. The patients relate death and dying to the bodily changes brought by cancer, and evaluate death as the ultimate bodily change, which also has social, psychological and philosophical connotations. The idea of dying of cancer makes most cancer patients reinforce boundaries between the private and public realms of their lives and to separate people who are close to them and the "others" in more definite terms. In that sense, having cancer and dying naturally follow each other, since dying of cancer further differentiates cancer patients from other, healthy people.

## Chapter 1

### Modernity, Social Transformation and Medical Realm in Turkey

“In Turkey, there are two groups of people who are separated by a wide gap in terms of their economic and cultural background. Unfortunately, 70-80 % of the population are below the gap... It is difficult for our doctors to go down to the same level with these people in order to treat them. The doctors have to talk to them as if they shout military orders. They have to be loud and brief and they cannot explain to the patients anything in detail, since the patients do not even have the capacity to ask for further explanations... As for me, the doctors in Güvercin Hospital have had such a correct attitude that I have trusted them hundred percent. The personal interactions in the hospital are wonderful and the staff treat me as if I am their brother. When my test results were good, they were even happier than I was. However, a patient who lacks a proper culture and education might have abused their concern for their patients.” (Altan, a colon cancer patient in his sixties)

“In my interactions with doctors, the only thing that is missing is to be beaten by doctors. The attitude of the SSK doctors was particularly rude. They shouted at me all the times, even if I was right and they were wrong. Once, two doctors began to shout at me, both at the same time. While I was listening to them and getting annoyed, two mopping sticks behind a door caught my eye, so I went up there, got them and gave one of them to each doctor and said that they would rather beat me with those sticks. They got surprised and laughed in an uncomfortable way...I wish I weren't sick and could beat them myself or I could at least see a doctor beaten by a patient in my life time.” (Abdullah, a lung cancer patient in his forties)

The quotes above point to two highly different types of medical institutions and doctor-patient interactions in İstanbul, Turkey. They also belong to two cancer patients who differ from each other considerably in terms of their social background and views on Turkish modernity, and if they ever met in a hospital or elsewhere, their encounter would likely be an uneasy one for both of them. The cancer patients' social interactions and categorization of "good" and "bad" patients by the medical staff, shape their illness experiences and narratives to a large extent. Those categorizations are informed by how the patients fit or do not fit into the criteria set by the modernist ideology which results from the particular historical interaction between medicine and modernity in Turkey. However, most patients do not passively internalize those categorizations or readily accept the close association between medicine and modernity. Rather, they criticize the elitist and discriminatory aspects of the ideology and the ways in which those aspects are reflected in the health care providers' attitude and behaviors. Those criticisms are also related to changing conceptions of modernity and the popular wish that alternative modernities can exist together peacefully in Turkish society and in medicine. In this chapter, I will argue that the recent social changes in Turkey, such as mass migration to the cities and rising Islamism, created a suitable environment for the expression of those criticisms, and also inform the patients' illness narratives. I will describe two "medical neighborhoods," Güvercin and Okmeydanı, with a focus on how these neighborhoods are affected by social change and the ways in which this is reflected in the medical realm. I will briefly describe Güvercin Hospital, situated in Güvercin, and SSK Hospital, situated in Okmeydanı, and discuss how the patients who attend those hospitals reflect the socio-economic diversity in Turkey. I will also discuss the life stories and illness narratives of

two typical cancer patients in these hospitals, in order to illustrate the connections among the patients' socio-economic background, illness narratives and Turkish modernity.

**The Social Transformation and Critique of Modernity in Turkey:** Since the 1980s, social scientists in Turkey and elsewhere have questioned the concept of modernity and modernist ideologies through ethnographical research and theoretical debates. Rather than coming to an agreement about these issues, they point out the complexity of the notion of modernity, especially in shaping the dynamics of power and culture both locally and globally (Knauft, 2002). Modernity is closely related to notions of progress and development, but Jonathan Friedman (2002) notes that other than these concepts, it includes a “laundry list” of terms, such as individualism, public/private division, democracy, nation-state, enlightenment philosophy and capitalism, which are hard to relate to each other systematically. This problem is also true in Western societies where the idea of modernity and the notions that are related to it originate. However, according to Bruce Knauft (2002), modernity is a more complex condition in non-Western, especially post-colonial, societies where Western modernity is imposed through different political institutions and cultural processes.

Although Turkey has not been colonized in political terms, it experienced a process of modernization similar to that of the colonized countries when both Westerners and Turkish ruling elite introduced and imposed Western notions of modernity during the Ottoman Empire and later in Turkey. This introduction of Western institutions and modernist ideas can be considered also to be indirect or internal colonization. These

processes resulted in a radical social transformation, and also created resistance, new public debates and political conflicts.

Modernization became the official policy of the Turkish republic, which was founded in 1923 by Mustafa Kemal Atatürk, who later on inspired the birth of Kemalism. In accord with his “universalistic claims and aspirations,” Mustafa Kemal envisioned “an organized, well-articulated, linear process of modernization through which the whole nation was going to move simultaneously” and have a uniform experience. (Bozdoğan and Kasaba, 1997; Kasaba, 1997) As a result, Kemalist Turkey would be a “militantly secular, ethnically homogenous republic well on its way to catching up with the civilized nations of the West.” Although the modernization efforts were initially described as a social project, which concerned every individual, being modern is largely associated with a secular and urban Turkish elite (Navarro-Yashin, 1998, Arat, 2001). Therefore, the unitarian and hierarchical aspects of Kemalism have failed to address the socio-cultural diversity in Turkey, which became more pronounced and visible in the political and public realm since the 1980s.

The social changes in recent decades, mainly the increase in migration from rural areas to the big cities, the rise of political Islam, and the shrinkage of state’s social and economic power, have increased social tension and polarization (White, 2002). Since traditional alliance between the urban upper and middle classes and Turkish modernity has largely broken down, it has become possible to conceptualize alternative versions for Turkish modernity. Reşat Kasaba (1997) explains that “the Turkish experience appeared to be culminating in economic backwardness and social flux, with Muslim and secularist, Turk and Kurd, reason and faith, rural and urban...existing side by side and contending with, but more typically strengthening, each other.” The polarization between each of the

“sides” has increased, both in terms of underlining the socio-cultural differences between these sides and creating a political tension based on those differences. The polarization also became visible through the cultural symbols which mark identity and allegiance, such as women wearing a headscarf, people wearing pins with the colors of the Kurdish movement (red, yellow and green) or large pins of Atatürk, and people hanging Atatürk’s pictures and Turkish flags in their houses (Kandiyoti, 1997; Göle, 1997).

Deniz Kandiyoti (1997) argues that “the state-led modernization is an alien and alienating project, inviting local attempts at resistance and subversion” and that the new social movements, such as Islamism could be interpreted within this framework. In today’s Turkey, those attempts are no longer local or marginal, and they can be interpreted as efforts to conceptualize a new version of Turkish modernity. Turkish modernity has been subjected to changes and criticisms since the earlier efforts of modernization in the Ottoman Empire. However, the efforts of the “others,” who were previously alienated by Kemalism, to visualize and work towards creating a different type of modernity, which is more democratic and pluralistic in character, have been acknowledged by the rest of the society only since the 1980s. Similar efforts, which transform modernity into more “regional, multiple or vernacular in character,” also take place in different parts of the world, and thus the conception of modernity is problematized and subject to change at a global level (Knauff, 2002).

Although several scholars and intellectuals praise those efforts in Turkey, the Kemalist elite feel threatened by them, since their adherence to a Kemalist version of Turkish modernity still helps them to maintain their social and political status. Therefore, the elites have increasingly differentiated themselves from the “others,” less by their economic power, than by their “orientation toward an urban, secular, Western life

style” as opposed to the “lifestyle of the rural and provincial population, in which Islam played a fundamental role.” (Kasaba, 1997; White, 2002). That also enables them to keep the Kemalist project alive and to consider the alternative conceptions of modernity as marginal, despite the fact that the people who construct these conceptions are increasingly becoming more powerful in political and economic terms.

Despite recent social changes and public debates, the distribution of political power and social support is still highly imbalanced in favor of Kemalist elites, because of the close association between Kemalism and the Turkish state. The modern Turkish state and its institutions are largely associated with Kemalist modernity, and they are seen as its guarantors for today and the future. The army, which has a considerable political power, is also one of the main defenders of Kemalist values. Moreover, the Kemalist endeavor to create the ideal citizens of the republic who are “enlightened, well-educated in positive sciences, secular, rational and Westernized,” still constitutes the essential principle of the mainstream public and private educational institutions (Acar and Ayata, 2002). Educational institutions, which have played a crucial role for upward social and economic mobility in Turkey, experienced the earliest attempts at modernization in the 19<sup>th</sup> century, and together with the army, were later given the role of raising Kemalist generations for the new republic.

On the other hand, the Islamists criticized Kemalist modernization as being “intrinsically antithetical to the essential qualities of Muslim culture” and everyday-life (Kasaba, 1997). Those criticisms gained more visibility with the recent rise of political Islam and the readoption of the head scarf for women, which has represented “strong self assertiveness and reconversion to Islam” for many newly veiled women since the 1980s (Göle, 1997). The rise of political Islam has constituted the biggest threat for the

Kemalist elites, particularly when the initially populist Islamist movement eventually created their own political and economic elite, who successfully claimed power and authority (White, 2002). The electoral victories of the Islamist Party since 1994 increased the sense of Islamic threat, and the Kemalist efforts against that threat became more widespread and organized. In response, the secular elite and intellectuals founded nationwide organizations, such as *Çağdaş Yaşamı Destekleme Derneği* (Association to Promote Contemporary Life) and *Atatürkçü Düşünce Derneği* (Association for Kemalist Thinking). These societies are still active today in carrying out the politics of identity, especially on the issues that are based on gender, such as the education of girls and women (Navarro-Yashin, 1998).

The rise of Islamism coincided also with the mass migration from the rural areas to the cities and the changes in the social life and structure of the city brought by the new migrants. As Meral Özbek (1997) explains, the migrants created informal networks based on “kinship, townsmanship and neighborhood relations within the larger urban setting,” and thus, preserved their sense of individual and communal identity through these networks. Those networks also helped them to maintain their lifestyle to a large extent, since they did not have to change their views, behaviors, dialects or the way they dressed in order to meet their basic needs, such as finding a job and having a house in the squatter areas or dilapidated neighborhoods of the city. The migrants created their own public space in the social, political and economic life of the city, and the urban elite saw that as a threat to their core values and identity. Since the mid-1980s, the urban elites have complained that “their city” increasingly looked like a village, in architectural, social, and cultural terms since the migrants built “their own villages” in the middle of the cities. Instead of becoming modernized and integrated into city life as expected during the early

waves of migration in the 1950s and 1960s, the migrants changed the social structure and cultural life in the cities to a considerable extent (Öncü, 2002).

The modernist elite also blamed the populist policies of the Islamist movement and political parties in recruiting followers among recent migrants who live in the squatter areas of the big cities, assuming an overlap between rural background and religion. This assumption is popular among secular, urban residents, since it enables them to draw rigid boundaries between themselves and the rural, religious “others.” The Kurdish separatist movement escalated and led to a civil war in the Southeastern Turkey in the 1990s, and that also increased the tension between the urban elite and rural migrants, many of whom migrated from the South East. Kemalists, who gave priority to Turkish citizenship over any ethnic or religious identities in defining the identity of “Turkish people,” also opposed the Kurdish movement and their claims for recognition of their ethnic identity.

İstanbul, as the cultural and economic capital of Turkey, experienced those recent social changes more vividly than other Turkish cities, because it is the city that always has received the highest number of migrants from Anatolia. Ayşe Öncü (2002) points out that there is also a familiar narrative of the invasion of İstanbul by successive waves of “outsiders,” who “threaten its authenticity and purity,” in the cultural imaginary of its middle classes. This has to do with lengthy history of “invasion,” “siege” and “assault” that the city experienced, as well as the waves of migrants who “endanger cherished distinctions of high and low culture.” Debates began to take place among different social groups in İstanbul in terms of who has a right to own the past and present of the city (Keyder, 1999; Bartu, 1999).

The power struggles between the Kemalist elite and the “others” also made the former shift their idealistic efforts to modernize the “others” and make them “ideal citizens” to waging a battle against them based on identity politics. This change in the elites’ attitude was a turning point which was also triggered when the elite realized that modernizing the whole society, especially the “others” who were becoming more vocal and visible, was not a feasible project. That turning point also has to do with the shrinkage of the political and economic power of the state, due to massive privatization in the country’s economic realm, educational and health systems, and the introduction of global capital to the country. Perhaps not surprisingly, health and education no longer strictly regulated by the state have become the main sites of confrontation and contest between Kemalists and the “others.”

The confrontation often takes place in both subtle and obvious ways, when the people who define their identity in different ways need to communicate with each other in their everyday lives. Joel Migdal (1997) argued that how the Turkish or any country’s project of modernity is adapted, resisted or reorganized is best understood through the analysis of the encounters between the modernist elite and the “stepchildren” who are “discarded” by that project. Such encounters include a constant effort to categorize “people like us” and the “others” in social and cultural terms. The Turkish medical realm provides an interesting context for such encounters, since it is historically associated with the Turkish efforts of modernization, as I will describe in the next section. Those encounters often includes a categorization of “good” patients, who fit into the hospital setting in terms of their views on modernity and social background, and “bad” patients, who are excluded by the Turkish modernity or who are critical of the interaction between modernity and medicine.

The experiences of “bad patients” felt often like “a test that they already failed even before answering the questions,” in Abdullah’s words, where both the health care providers and the “good patients” criticize them, since they do not fit into modern, medicine. That “test” is mostly a subtle one, and it includes the judgment of the patients’ general attitude, manners, clothing style and dialect, as well as the content of what they say. Obviously, the “bad” or “excluded” patients do not passively accept being tested, judged or possibly discriminated against, as Abdullah’s example above indicates, but express their wish “to be treated like a normal human being,” in Abdullah’s words, in different ways. Since cancer is a chronic disease, cancer patients spend so much time in hospitals, and they are required to make frequent hospital visits for several months or even years. Moreover, being a cancer patient affects their self-image, identity and social interactions outside the medical realm as well, during and even long after their cancer treatment. How do the “encounters” influence the patients’ illness experiences, and how are they evaluated in their illness narratives? How do such encounters influence the ways in which patients’ view Turkish modernity and its problematic aspects? Before discussing those issues, I will first describe the historical and current connections between Turkish modernity and medicine, which have an important role in shaping the interactions between the patients and health care providers and the “encounters” between the elite and excluded in the medical realm.

**Modernity and Medicine in Turkey:** In the 19<sup>th</sup> century, there was a common perception that the Ottoman Empire could no longer compete with European countries in political, economic and military terms. The frontiers of the country shrank considerably due to the wars that the Ottoman army lost against the European countries. As a result,

the Ottoman rulers acknowledged the necessity to transform the major political and social institutions in the country and model them after their European counterparts, in order to be able to compete with the newly powerful Western countries. Having an evolutionist and universalistic perspective, Ottoman intellectuals and rulers argued that the European states had reached the top level of modernity, and therefore Ottoman Empire had to follow their example in order to be a part of contemporary civilization (Hourani, 1992; Deringil, 1999).

The transformation began with the abolishment of the old army of janissaries and foundation instead of a modern European-style army, since the political and economic welfare of the Ottoman Empire largely depended on winning wars. The new military camps and barracks, where hundreds of soldiers stayed at the same time were also the ideal places for the common 19<sup>th</sup> century epidemics, such as tuberculosis, cholera and syphilis to start or spread among the soldiers and other people who interacted with them (Fahmy, 1998). Moreover, the Ottoman rulers also noticed that the European armies took better care of their wounded soldiers during the wars so that many of them even returned to fighting in the same war. These concerns led to the foundation of the first modern European-style military hospital, which would take care of the members of the army during war and peace. As the third European-style institution, a modern medical school was founded as a part of that military hospital in 1827, with the aim of teaching about the recent scientific and medical developments in Europe. For the Ottoman rulers, the first modern hospital and medical school were not only crucial for the improvement of the army but also for raising doctors who would bring health to the whole society, which also suffered from such lethal diseases as cholera, syphilis, malaria and tuberculosis (Gürsoy, 1996).

The number of Western style medical schools and hospitals increased in the 19<sup>th</sup> century, and studying medicine became a significant option for the sons of elite families, who wanted to raise valuable citizens for the modernizing society. The first generations of doctors who graduated from those schools saw themselves as both the pioneers and gatekeepers of Turkish modernity, thanks to their privileged access to Western science, technology, languages and culture, (Dole, 2004). The duty of the first generation of doctors was to solve the main health and social problems in their society in order to transform the “backward” Ottoman Empire into a truly modern society (Hanioglu, 1981). From the late 19th century until the 1980s, doctors enjoyed a high social status and professional prestige, since they came mostly from the elite families and had a “sacred” profession<sup>5</sup> (Öncel, 1951; Sezer, 1953). Especially during the transition from the Ottoman Empire to the Turkish Republic, which took place after a series of wars, such as the First World War (1914-1918) and Turkish Independence War (1919-1922), the role of doctors and biomedical services became crucial in creating a young and healthy population. Christopher Dole (2004) indicates that medicine obtained a vital position in creating that “new society,” since it was a project which was based on the inculcation of reason, rationality and science by people such as doctors who had already internalized the modernist and secular principles.

The political authority and social prestige of doctors increased considerably in the earlier decades of the new republic, which was founded in 1923, since they brought “enlightenment” in the shape of modern medicine and sciences to the remotest villages of

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<sup>5</sup>Doctors are popularly described as the “hand of God” in Turkey, because of their role as the messenger and helper of the God in creating and taking lives. The prestige and authority of doctors often prevent patients from discussing economic matters regarding their treatment and doctors have a principle of never receiving money from the patients directly.

the country, where people suffered badly from various epidemics and high infant mortality (Dole, 2004). Medicine became one of the main tools of the state to “modernize” the society, since the political aims of producing healthier generations and increasing the Turkish population led to the foundation of modern medical institutions throughout the country. Those aims also influenced people’s everyday lives by promoting scientific methods of child care, maintaining personal hygiene, and fighting diseases. Accordingly, the crucial role of doctors as “modernizers” was confirmed by the state and political elite, and the strong adherence to Kemalist project of modernization among earlier generations of doctors helped them to gain political authority and social prestige (Gürsoy, 1996).

The doctors’ pivotal role in the modernization of Turkish society and their social prestige related with this role were first challenged in the late 1960s, with the involvement of medical students and doctors in various leftist and rightist political movements. However, more major changes in doctors’ social positions and the interaction between medicine and modernity have taken place since the 1980s. As a result of the new pluralistic policies in the 1980s to accommodate more people in higher education, new public and private medical schools have mushroomed throughout the country, and the class size of existing schools increased considerably. This led to a decline in the quality of medical education in general, and heterogenization of the profession in terms of socio-economic background (TTB, 2002). There are now a considerable number of doctors whose families differ from the typical urban, elite families who traditionally sent their children to medical school. Moreover, they subscribe to a wide range of political opinions, which do not necessarily prioritize bringing modernity and enlightenment to the society. The later generations of doctors’ various

political opinions and activities also affected their association with the state and its modernization project, as I will discuss in the Chapters 2 and 3. Therefore, those doctors began to look for sources of social status and political authority other than their roles of dutiful modernizers.

The rapid increase in the number of private hospitals since the 1990s also furthered the differentiation among the doctors in terms of their economic power and political opinion. The fact that few of those private hospitals were founded by the new Islamist elite also furthered the political tone of the debate about the privatization in medicine<sup>6</sup>. Aslıhan Sanal (2004) notes that the “medical diaspora,” which had previously worked in the U.S. And in Europe, started to return to Turkey in order to work in the recently opened private hospitals, which altered the standards of an ideal health care system because of their “Western- educated doctors and high-tech hospitalization.”<sup>7</sup> Private hospital wages are about three or four times higher than those of public hospitals; therefore, they also provide an important source of upward mobility for doctors from disadvantaged backgrounds. However, economic mobility does not readily translate into social and professional prestige for the doctors in private hospitals, since many doctors who work in the public hospitals blame them for prioritizing their own interests over the social problems.

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<sup>6</sup> The data, which I discuss here, is derived from the ethnographic research, which I conducted for my master’s thesis: “Turkish Medical Doctors: Historical Experience and Self- Narratives” (1998). I updated that data in 2003 in order to use it in an article, which is based on my master’s thesis.

<sup>7</sup> The problem of “brain drain” is a public issue in Turkey, especially in the case of Turkish doctors who work in Europe and in the United States. This problem stems from the shortage of well-qualified, knowledgeable and skilful doctors and the regional inequalities in the distribution of doctors, as well as health care services in Turkey. The private hospitals alleviate that problem, only to some extent, since they are concentrated in the big cities, such as İstanbul, where the 111 out of 137 licensed hospitals are private (Sanal, 2004).

The debate about the privatization of medical care also includes a generational conflict between the “idealist” previous generations and “selfish” new ones, since the private hospitals often recruit young doctors whose relations with patients are thought to be good. That debate also reflects the recent social changes, since it differentiates the doctors who pursue their profession mainly in order to improve society in accord with the modernist principles from those who prioritize their own economic interests (Terzioğlu, 1998, 2004). The turning point that led the Kemalist elite to understand that modernizing the *whole* society with a top-down approach is impossible is also influential in shaping the views of doctors on both sides of the debate, especially those of the “selfish” ones. Similar to the categorization of “good” and “bad” patients, the modernist doctors also differentiated the “good” doctors, who are like them, and the “bad” doctors, who do not care about the “backwardness” of their society, in terms of health conditions and social problems. That differentiation enabled the modernist doctors to see themselves as “good doctors,” who still associate their profession with Turkish modernity, despite the recent social changes and heterogeneity among doctors in terms of their socio-economic background, political views and professional goals.

The recent heterogeneity in doctors’ socio-economic background and political views is related with the recent social changes and polarizations in Turkey, and they also affected the professional solidarity among them. Since the late 1980s, the media have covered the series of demonstrations of female students who protested the ban on their headscarves and veils in the medical schools, which are often more crowded, and which have caused more public attention than the similar demonstrations in other faculties did. Similarly, the Turkish Chamber of Medicine also includes the polarization between the “Islamist” and “Kemalist” doctors who compete with each other in the elections of the

Chambers' directory board. When I was studying in the library of that organization during my fieldwork, I talked to several doctors who gathered to "lobby against" the "Islamist" doctors, and who told me that medicine is the last bastion of Kemalist modernity and that they would do everything not to lose that bastion.

On the other hand, most Islamist doctors prefer to be called "religious," similar to the "Islamist" patients I interviewed, and write books about how Islamic views and practices, such as praying and reflecting on God's greatness, help patients to gain the high morale that they need during their medical treatment (Nurbaki, 1982). Another "Islamist" doctor I met at a conference during my fieldwork emphasized that he does not oppose the basic premises of modern sciences and medicine, but that he questions the link between medicine and Turkish modernity in general. He worked in a private hospital, which is also known as 'Islamist,' and he also believed that he is a better doctor than many Kemalist doctors, since he knew how to interact with the religious patients properly.

The association between medicine and modernity is also present in the society in general, not only because of the historical role that doctors played in the foundation and inculcation of Turkish modernity, but also because of the ways in which the health care institutions represent the latest scientific and technological developments. As Altan argues "applying a routine medical test or preparing a chemotherapy drug includes such complicated and advanced medical knowledge and scientific technologies" that amazes "even the patients, who do not know much about positive sciences." The association between medicine and modern scientific knowledge and practices also make the cancer patients trust in the efficacy of medical practices in the hospital and to respect the doctors' judgments and advice. Figen, a breast cancer patient in her thirties, explained that the big hospitals in İstanbul are so well equipped that the doctors have the means to

see and interpret “whatever happens in a person’s body down to the tiniest part of it.” Figen emphasized that whenever she has a serious health problem, “she would not think about going anywhere else, but to the hospital,” since she believes that they provide the best health care there, in contrast to the places, where people are treated with complementary or alternative medical practices.

The association between medicine and modernity also leads medical staff to take an ideological position against complementary or alternative medical methods, as I will describe in Chapter 2, and impose that position on their patients. As a result, many patients accept that position in principle, but do not behave in accord with it in their everyday lives. Most patients I interviewed favored modern medical knowledge and practices over complementary or alternative medical knowledge and practices for cancer treatment and other health problems. The patients’ attitude towards alternative or complementary medicine varied from trying it just out of curiosity to thinking that it is performed by “charlatans” who abuse the patients’ hopelessness. On the other hand, 42 out of 50 patients had resorted to at least one type of complementary or alternative medicine informed by the popular interpretations of Islam, local knowledge of health and illness, or by newly popular healing methods, such as reiki, positive energy and yoga<sup>8</sup>. Although most of those patients were also apologetic about benefiting from different medical models, they also related this to their disappointments in the biomedical institutions and the criticisms of the health care providers’ attitude towards them. As I will discuss further in Chapter 5, the cancer patients often experience a dilemma between

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<sup>8</sup> I will discuss the common alternative medical methods in treating cancer and the popular and medical views on these methods further in Chapter 3 and 5.

the ideal image they hold of modern sciences and medicine and their actual experiences and impressions in the modern medical institutions.

The patients' illness experiences, views on modern medicine and the attitude of health care providers vary considerably depending on whether they have their cancer treatment in a private or public hospital, as I will discuss in the next section. That difference basically stems from an economic factor, since the public hospitals take care of the patients who cannot afford private insurance. Accordingly, most of the patients who attend public hospitals are clergy, low-skilled and low-paid workers, farmers, and small tradesmen (Sanal, 2004). However, the patients who "have to" be treated in the public hospitals do not necessarily benefit from inferior medical care compared to patients who have means to have their treatment in private hospitals. Nevertheless, the illness experiences of the public and private hospital patients differ considerably in terms of social interactions with the medical staff and bureaucratic arrangements.

The differences between public and private hospitals also reflect the social and economic developments in their neighborhoods, and play a major role in shaping those developments. The neighborhoods of SSK and Güvercin contrast sharply with each other in terms of the socio-economic background of the people who live there, as well as the medical and social facilities that are provided. Therefore, the social interactions that patients experience in these hospitals, and the socio-economic characteristics of the two neighborhoods, reflect these interacting social and geographical circumstances.

**Two Medical Neighborhoods, Two Hospitals:** Güvercin, where the Güvercin hospital is, and Okmeydanı, where the SSK hospital is, are marked by the several hospitals, clinics, medical laboratories and pharmacies, which so shape the social life of

those neighborhoods that they can be called as “medical neighborhoods.” Both neighborhoods are in the European part of İstanbul, and are roughly 20 minutes away from each other by car. However, despite their geographical proximity, these two neighborhoods differ from each other in terms of their social and cultural characteristics, and recent changes have significantly increased that contrast. Like the residents of those neighborhoods, the patients who frequent the medical facilities in Güvercin and Okmeydanı differ in terms of their socio-economic background. The Güvercin neighborhood and the Güvercin Hospital are largely associated with the dominant urban elite, whereas Okmeydanı and the SSK Hospital, with the rural, religious and the threatening “other.”

The “Güvercin Hospital”<sup>9</sup> belongs to the Turkish Association for Cancer Research and Control, which is one of the main private cancer associations in Turkey, and is situated in the Levent district, which is becoming one of the main economic centers of the city. Güvercin, originally a quiet, residential, middle class neighborhood, has changed significantly since the 1990s both because of the opening of several large-scale, private medical facilities, and the economic boom in the nearby neighborhoods of Etiler and Levent. Taking its name from the many pigeons in its forest<sup>10</sup> (Güvercin was once the home of a large forest), a housing development started there in the 1950s, and by 1965 it had gained its middle class identity, inhabited by state employees, army officers, teachers and scholars (Kaya, 2004). Until the 1990s, Güvercin remained a small, calm and isolated neighborhood with a suburban feeling, mostly because it was connected to one of the city

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<sup>9</sup> The full name of the Güvercin Hospital is the “Güvercin Hospital for Cancer Control and Research.” However, many patients and health care providers call it simply “Güvercin Hospital,” also because of its association with the neighborhood.

<sup>10</sup> Güvercin means pigeon in Turkish.

centers, Taksim, only through the public bus service. Nevertheless, the residents of Güvercin neighborhood had good living conditions, and enjoyed facilities such as playgrounds for children and tree-lined large streets.

In the 1990s, the headquarters of the biggest Turkish and multinational firms and banks, as well as American style large-scale malls, were found in the main streets of Levent and Etiler, and the Güvercin neighborhood became a hinterland in the area. Cozy cafés and restaurants, well-equipped sport centers and chic boutiques were opened in Güvercin in order to cater to the needs of the white-collar workers in those businesses, and they brought a more vivid and up-scale social life to the neighborhood. As Güvercin began to symbolize the modern and global life-style many residential buildings were also renovated and the upper-class elite began to live or spend time there. Güvercin has also had better connections with the city, thanks to the increase in the frequency of bus services and the foundation of a new subway line in 1998, which connected Levent district to Taksim.

Several hospitals, clinics, pharmacies and laboratories were also founded in Güvercin in the 1990s and 2000s, and they became highly popular among the middle and upper class people who live or work nearby and in İstanbul. Besides the cancer hospital, where I conducted my research, there are now two large-scale private hospitals and an internationally acclaimed eye hospital, which play an important role in defining this neighborhood as a medical one. One of those hospitals started to cooperate with the American Metropolitan hospital in 2005, which has increased its fame and prestige even further. Around these medical institutions, there are several private clinics of dentists, dieticians and doctors, as well as “medical centers” specialized in treating eating disorders, especially obesity, which is becoming an important problem in children of

upper-middle class families. There are also clinics, where the newly popular alternative medical methods such as acupuncture and positive energy are applied. The medical institutions have also made the Güvercin neighborhood more prestigious and attractive for the elite, as well as for the middle class people who are looking for better health services.

Güvercin Hospital, as noted earlier, is a private hospital, which is specialized in all types of cancer treatment, and it is popularly known among the cancer patients in İstanbul for its better doctor-patient relations and higher quality of health care, compared to the standards of Turkish medical institutions in general<sup>11</sup>. I carried out part of my fieldwork in this hospital mostly because the health care providers welcomed a social science researcher like me, since they acknowledged that having cancer involves crucial social and cultural dynamics. It is a small hospital with five full-time and three part-time doctors who treat 20-30 patients a day. Although, the hospital is private, its fees are lower than other private hospitals, since the Turkish Association for Cancer Research and Control, private donations, and the state cover most of its expenses. The patients who regularly attend the cancer hospital in Güvercin come mostly from the same neighborhood or nearby areas. However, the hospital, which was founded in 1986, is increasingly well known all over İstanbul, so more people now come to this hospital from distant neighborhoods, or even from towns on the outskirts of İstanbul. One of the nurses told me that in the five years since she started to work here, she has noticed relatively more economic and social diversity among patients.

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<sup>11</sup> I will describe the social and physical environments in the Güvercin and SSK hospitals further in Chapter 4, where I will also discuss how the attitudes of nurses towards the patients differ from those of doctors in those two hospitals.

Unlike Güvercin, Okmeydanı<sup>12</sup>, where the SSK Hospital is situated, is just ten minutes away from Taksim by bus, and it is also on the cross-section of several highways, which connect the main parts of the city. It is a much older neighborhood than Güvercin, and its name comes from the Ottoman army's practice with bows and arrows in that neighborhood (Kaya, 2004). The SSK Hospital, which is the third largest public hospital in İstanbul, includes about twenty buildings that are scattered in the hospital area. That is why the neighborhood is commonly associated with the SSK hospital in İstanbul, since the hospital provides medical services to a large number of patients who come from the different parts of the city and it covers a large physical space in the neighborhood. Around the SSK Hospital, there are also several private clinics and laboratories where patients can have medical tests without waiting for too long and without too much bureaucracy. The first clinics at SSK Hospital were founded in the early 1940s, and the hospital has continuously expanded until today. However, there has been a considerable decline in the quality of medical services and prestige of the hospital, in accord with the budget cuts and increase in the number of patients since the 1980s, a decline that went together with that of the neighborhood in socio-economic terms.

Okmeydanı neighborhood was a typical middle class neighborhood before the 1980s, and its residents were not very different from those of Güvercin in terms of their socio-economic background. The old İstanbulite families lived in the 19<sup>th</sup> century neo-classical Ottoman houses, and newer apartment buildings, which were built in the earlier decades of the republic (Kaya, 2004). However, in the 1980s and 1990s, the newer generations of those families began to prefer newer and more vibrant neighborhoods, which have gardens, parks and larger side walks, in the nearby districts of Gayrettepe,

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<sup>12</sup> Okmeydanı can be translated as Bow Square into English.

Esentepe and Mecidiyeköy. They also preferred to live in the more recently constructed modern buildings, instead of paying large sums of money in order to renovate their old places, which were deteriorating rapidly. Those people were rapidly replaced by the recent migrants from Anatolia, who had other priorities than renovating those houses, which became increasingly dilapidated.

The migrants opened coffee houses, small shops and workshops in Okmeydanı, which also drew more migrants to the neighborhood. Those “traditional” coffee houses provide a striking contrast to the cozy, Western-style cafés in Güvercin, and they are dominated by men, who establish or strengthen their “informal networks” there, which are based on kinship, townsmanship and neighborhood relations. The coffee houses provide new migrants an opportunity to exchange information on crucial topics, such as job openings, which help them to survive in the city. However, those communal ties are also affected by the large highways, which cut through the residential areas, and the rifts among the migrants who came from different regions of Anatolia at different times. Despite the problems among them, Okmeydanı is now commonly associated with the migrants in the city who are seen as the “others” who “invaded” and transformed the city, creating their own public space. Therefore, Okmeydanı became a neighborhood that the old elite of İstanbul avoided to a large extent, and it suffered from the vicious circle of stigmatization and isolation from the “modern” parts of the city.

Besides the dilapidated buildings, the “threatening migrants” and the dominance of low paid jobs for the unqualified workers, Okmeydanı has also suffered from the environmental problems since the 1990s. Despite the constant efforts of the municipality to keep the area clean by posting notices that say “please keep the neighborhood clean” and cleaning the streets twice a day, one can often see garbage bags of different sizes

thrown on the streets. Because of the highways and the buses and minibuses that frequently pass through, Okmeydanı has highly polluted air, and both the district and city municipalities are trying to solve this problem. In the recent years, the district municipality cooperated with the a couple of well-known businessmen, whose families also once migrated to İstanbul, to upscale the neighborhood by providing new job opportunities for the residents. As a part of those efforts a new convention center and a vocational high school were opened in Okmeydanı, which may play a role in changing the social and economic life in Okmeydanı in the future.

As I mentioned above, the SSK hospital in Okmeydanı also suffered from a similar loss of social prestige along with the rest of the neighborhood, and plans to improve the hospital were activated recently as a part of the health care reform project. The official name of SSK Hospital is *Social Sigortalar Kurumu Araştırma Hastahanesi*, which can be translated as Research Hospital of Social Security Institution. This public hospital provides much cheaper health care than most public hospitals as well as free medical care and medication for workers who are employed by the state, and for their immediate family members. With the privatization in medical care, the prestige of the state hospitals, including SSK, has decreased compared to the recently opened private ones in the 1990s. Many people, including 14 of the patients I interviewed, complain about the tedious bureaucracy, crowd of patients, long waiting periods, harsh attitude of medical staff and inadequate hygienic conditions at SSK. They also state that they may prefer to visit private hospitals once in a while in order to avoid those problems, although their SSK insurance does not cover their high fees. Nevertheless, many people, including eight of the patients I interviewed, still believe that the medical care is superior at SSK. SSK hospital has an essential and irreplaceable position in the Turkish health care system,

since it is visited daily by hundreds of patients who are in the lower tiers of the state employment, and who cannot afford any other hospitals. Many patients also visit SSK from the remote parts of İstanbul, as well as from the nearby cities, since they believe in that they can have the best medical treatment with the lowest fees or without any fee in case they have the SSK insurance, which covers their medical examinations or operations.

The fact that SSK is a “research hospital” also attracts many people, who ask for a thorough examination and a detailed diagnosis afterwards, especially in the case of cancer patients. For instance, Feriha, a breast cancer patient in her sixties, argued that a research hospital is “a sacred place, just like a mosque with a good imam, who knows the Quran by heart and who can recite the parts of it easily whenever it is needed.” She added that SSK doctors know exactly what parts of her body have cancer and use their professional expertise through medical tests and research, just as the imam knows when his religious expertise is needed. Through research, she added, the “scientists” will discover exactly where the cancerous cells are located in her body, and that is why the research will make the difference between surviving cancer and dying because of cancer<sup>13</sup>. Feriha kept emphasizing the word research, saying it slowly and slightly raising her voice, which sounded as if she was attributing a sacred meaning to the word. Therefore, the problems I mention above do not necessarily affect the quality of medical care according to many patients, who prefer SSK hospital for their treatment despite their complaints about the crowd, bureaucracy, tense interactions and filthy wards, waiting rooms and corridors.

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<sup>13</sup> There is a strong association between cancer and death in the Turkish society, and the Ministry of Health, several cancer associations and health care providers try to eliminate that association, by organizing large-scale campaigns throughout the whole country. That association will be discussed further in the chapter 3 and 8, but it is important to note that cancer patients’ trust in modern medical institutions and medical staff become crucial when patients believe that a slightest mistake during their treatment may lead to a death because of cancer.

The oncology section of the hospital where I conducted my research, was founded in 1974, and has 21 doctors, most of them well known in their fields. In addition to its oncology clinic, SSK has every medical specialization and several research centers with laboratories. There are two large squares and several small gardens among the numerous hospital buildings. Because of the large number of patients and budget problems, the hygienic standards are low, and that is reflected in soiled bed sheets that remain on the bed for hours after the patient who occupied that bed has left, and the garbage from too-small garbage cans littering the hospital and carpeting the ground in the gardens and backyards. The waiting rooms and wards at SSK are darker, shabbier, smaller and much more crowded than those in Güvercin, and the patients-staff interactions are more tense, aggressive and impersonal in general. The politicians, scholars, health care providers and media often cite SSK Hospital as the primary example of the problems affecting Turkish medicine, which are embodied in over-crowded hospitals with complicated bureaucracies. Unlike my experience in the Güvercin Hospital, I had bureaucratic difficulties in getting permission for my research, since the doctors who run the clinic did not have time to go over my application for several weeks. I had to overcome this problem through my personal connections to the doctors who worked in the oncology clinic of SSK.

**The Life Stories of Patients from the Two Medical Neighborhoods:** The cancer patients' illness narratives are embedded in their life stories, and reveal how the patients' socio-economic backgrounds influence their expectations from their social interactions with the health care providers. Although the typical patients at SSK and Güvercin hospitals differed from each other in terms of socio-economic background,

several patients visit both hospitals for different reasons or for different parts of their treatment. As the contrasting quotes of Altan and Abdullah cited earlier, the ability to pay for private health care services, and sharing similar socio-economic status with health care providers, help the patients to establish better social interactions in the hospital. For the chronically ill patients whose medical treatment shapes their everyday life for at least several months, having better social interactions in the hospital is a crucial issue, for some, such as Abdullah who mobilized most of his economic resources in order to be treated in Güvercin Hospital instead of SSK. On the other hand, there are patients, such as Altan, who take having equalitarian and friendly social interactions with the health care providers for granted and think that they deserve it, since they consider themselves to be the “good patients” who fit into the modern, medical realm in social and cultural terms. The life story and illness narrative of Altan and Abdullah also give us clues about how the contrasts in their illness experiences are shaped by their family, education, profession and views about modernity and modern medicine.

Altan, the Güvercin patient, was born and raised in İstanbul, where he attended Saint-Michel, a private French high school founded by Catholic missionaries in the 19<sup>th</sup> century, and then İstanbul University, Faculty of Architecture. His father was a high-ranking officer in the army, who worked in different parts of Anatolia, where Altan also visited during his childhood. When Altan became an architect, he founded his own company and supervised numerous construction projects for more than three decades, such as the İstanbul Technical University’s campus, several large-scale industrial complexes and holiday resorts around İstanbul and in the Aegean Coast. Recently retired, he was planning to move to a village in the Aegean coast when he was diagnosed with cancer. He is married and has a daughter who studied business at Cornell University after

attending French high school, and who became a businesswoman in a multinational firm in İstanbul. Altan is proud of his daughter's education in the US, which he considers the most developed country in terms of science, technology and education. Altan argued that Turkey remained backwards in these respects, because the rulers after Atatürk did not pay enough attention to these issues. He is a firm believer in the Turkish modernization project and Kemalism, which brought the "light of civilization" from the West to the Ottomans, who "did nothing for centuries, but just creating a synthesis of the culture of the minorities, such as Greeks and Armenians, in the country." He also contrasted İstanbul with Anatolia, where he "saw every single remote corner" both during his childhood and professional career. He argued that although the "light of civilization" has reached to most old İstanbulites, there are "thousands of people in Anatolia" who still remain in the darkness and who do not know how to behave properly in a civilized world, "as one can also observe in the recent migrants from İstanbul to Anatolia."

When Altan was diagnosed with colon cancer, he immediately consulted with his son-in-law, who is a manager in a well-known pharmaceutical company and who knows many well-known doctors. Altan was near the end of his cancer treatment when I talked to him, and he was having three extra chemotherapy sessions in Güvercin Hospital, where he has had most of cancer his treatment, in order to make sure that the cancer cells in his body are totally eliminated. As his quote above indicates, he was very happy with the treatment and social interactions he has received in Güvercin and in another private hospital, where he visits a doctor to confirm the interpretation of the tests he had in Güvercin. He also lives in a house in the Güvercin neighborhood and therefore is glad to be able to walk to these hospitals. Altan was sure that the doctors have the knowledge and skills to cure his disease, and he believed in the superiority of scientific knowledge

and modern medicine, which depends on scientific research methods, and the precise knowledge acquired through these methods. He also evaluated the “warm attitude of health care providers,” who treated him as if he is “their brother,” as normal and natural, since “they all spoke the same language,” and therefore “understood each other better than in the case of most other doctor-patient interactions.” Altan said that he never resorted to alternative or complementary health care methods, since he thought that they were not based on positive sciences. However, after the interview, his daughter, Aysel, told me that she took reiki classes, where she and other participants sent positive energy to her father in every session. Altan and Aysel, then, had a brief argument about whether reiki is scientific enough to gain Altan’s respect.

Although the class structure is hard to define in Turkey, Altan’s educational background, his profession, his house in Güvercin neighborhood, and his two summerhouses where he plans to stay after his cancer treatment is over qualifies him as a person with an upper-middle class background. He also considered himself a product of an elite and a truly Kemalist family, and he emphasized that he did his best in order to live in accord with the Kemalist values that were given to him by his family, and to inculcate the next generations with those values. His Kemalist and elite background help him to differentiate himself from the other, “bad patients,” who constitute 70-80% of the whole patients, and “who do not know how to ask for further explanation to their doctors.” According to Altan, the success of this elite group is directly related to the fact that they had a good education in the top schools of Turkey and of the world. He believes that the problems in the health sector, similar to the other social and economic problems in the country, stem from the lack of “proper” education of the %70-80 of the population, who “abuse the modern medical system because of their ignorance and backwardness.”

His argument, which is also shared by many Turkish doctors, can be interpreted as the population who lacks a proper education is also prone to non-compliance during their medical treatment.

Abdullah, on the other hand, had received only a primary school diploma. Speaking with a thick “villager dialect” and “always proud of being a villager and behaving like one,” Abdullah can be considered among the 70-80% of the population, who “abuse the modern medical system,” according to Altan’s evaluations. Although Altan and Abdullah have not met, Abdullah was well aware of the fact that many health care providers and patients think that he is “backward and ignorant”; nevertheless, he tries hard to have better social interactions in both SSK and Güvercin hospitals. It was understandable that he was proud of his eventual economic success in the city, from the way he talked about his economic struggles after he migrated to İstanbul. His economic success prevented him to some extent from being viewed as an “ignorant villager” in his everyday life and in the the hospital, but he also said that he always has to have “an enormous amount of self-confidence” in trying to adapt to social life in İstanbul. Abdullah is a typical patient of SSK hospital, in terms of suffering from the negative attitude of health care providers there, although his frustration because of that attitude made him to continue his treatment at Güvercin Hospital later on. Abdullah and his family members never had any health insurance for a long time, and Abdullah explained this lack with having a healthy family in general and his wife’s giving birth to their children in their village with the help of a nurse in the local health clinic. However, his son who became regularly employed and had the SSK insurance few months before Abdullah was diagnosed with cancer. Abdullah, as the immediate family member, benefited from that insurance for his tests and earlier phase of his cancer treatment.

Abdullah came to İstanbul from a little village near Sivas in Central Anatolia after marrying in his early twenties. He said that he did not learn much in the village primary school, and that İstanbul was his real school, where he learned “every good and bad thing.” In İstanbul he worked in several restaurants, gradually moving up from dishwashing to opening his own small-scale restaurant in his neighborhood, which is inhabited largely by migrants from his own town, as well as by university students, who also often came from other towns to study. Finally, a year before our interview, Abdullah started to build a three-story house for his family. They lived on the first floor when I visited them for interviews, although the construction was not yet completed. The upper floors and exterior of the house were not yet painted, since Abdullah was diagnosed with lung cancer a few months after starting the construction and he could not work supervise and help the construction workers during his medical treatment. Abdullah believed that his sons will help the workers to complete the construction in the summer, and they will all “finally have their family house, which they dreamed about for a long time.” He also decided to continue his treatment at Güvercin hospital, because of the problems he experienced at SSK, and to use his savings for his cancer treatment.

Despite his relative economic success compared to many other migrants, Abdullah still badly misses the life in his village, which he visits almost every summer.<sup>14</sup> He proudly emphasized that he that he did not change his “villager tastes and habits,” showing the decoration of his house, the clothes he wears and the music he listens as examples, despite his upward mobility in economic terms. However, he encouraged his

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<sup>14</sup> The theme of nostalgia for the village life, which I will discuss further in chapter 5, came up in several other illness narratives that I have collected. Especially the first generation of migrants argued that the village life is healthier, and some of them went even further by saying that they would never have cancer if they did not migrate to the city.

three children, especially his daughter, Gül, to have a good education, “to dress up and behave like any modern city girl,” so that they would fit into the city life. As a result, Gül speaks with an İstanbul dialect and often corrects her parents’ strong Eastern dialect, both in their interactions with medical staff and during the interview that I conducted.

Abdullah is a good example of how economic mobility in İstanbul does not readily translate into the social mobility and acceptance by the elite, who may often see him as a “successful invader” in “their own city.” That negative attitude was also reflected in the attitude of the health care providers at SSK hospital, where Abdullah was diagnosed with lung cancer and had his first two sets of chemotherapy. As his quote at the beginning of that chapter indicates, his interactions with the health care providers at SSK were tense and aggressive, since, he thought that they saw him as “an ignorant villager, who has nothing to do in a big city like İstanbul.” He said that when he mispronounced a drug’s name or made a tiny mistake like that, doctors or nurses took that as an opportunity to “scold him as much as they can.”

Abdullah was so annoyed with the aggressive and condescending attitudes of the health care providers at SSK that he decided to attend Güvercin Hospital for the rest of his medical treatment, even though this change brought substantial economic difficulties to him and his family<sup>15</sup>. The construction of their family house stopped, and his daughter, Gül, “took a break” from studying at high school in order to work as a cashier in a supermarket on a part-time basis, accompany him in his visits to the hospital and helping her mother at home. The decision of continuing cancer treatment in a private hospital, despite its financial burden, is not unusual among cancer patients, since seven of the

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<sup>15</sup> My research indicates that it is very common for the Turkish cancer patients to visit several hospitals during their treatment and have different parts of their treatment in different hospitals, mostly due to financial issues and the problems in their interactions with the health care providers.

cancer patients I interviewed made the same choice. That strategy is also common among many chronically ill patients who need a long-term treatment, even if it requires mobilizing all the financial resources for that treatment, which is not necessarily more effective in medical terms than the treatment at SSK, or in any other state hospital (Keyder et al, 2007). This indicates the importance of social interactions in the hospital, especially for the chronically ill patients. Abdullah said that the health care providers treat him much better at Güvercin Hospital, but that he still feels alienated, since they mostly prefer to communicate with Gül rather than with him, “when they want to say something important” about his disease or treatment. The staff at Güvercin Hospital often praises Gül for being modern and open-minded when she is in the examination room with her father and after she leaves the room. Abdullah also often repeats that he is indebted to his daughter without whom he would feel lost in the Güvercin Hospital. Gül may represent a good example of a gradual cultural integration in the next generation, but this largely depends on whether she will resume her education after her father’s treatment is completed and find a good job. Alternatively, she may marry someone from her neighborhood or the migrant community and become a housewife like her mother, although she emphasized that she wants to continue her education and have a “respectable profession,” such as teaching in a high school or being an architect.

It is significant that Abdullah still respects and believes in the efficacy of his medical treatment, whether it takes place at SSK or Güvercin hospitals, despite the problems he experienced in his interactions with the health care providers in both hospitals. He thought that his medical treatment is essential for the treatment of his disease, which became a priority for his whole family. Although he occasionally used complementary medical methods, such as drinking the water brought from local saints’

tombs and eating mixed seeds and fruits prepared in the herbalists' stores, he said that he used those methods mainly because his wife and aunts insisted. He added that he does not "even compare those witchcraft-type medicines" with the medical treatment that he has in the hospital in terms of efficacy, since "all that medical knowledge, technology and expertise" can not be compared to the ancient, folk remedies. Abdullah ultimately approves of the biomedical system and modern city life, which he is inevitably a part of and which he "can not just give up." However, he claims to be a part of that modernity on his own social and cultural terms, and he demands respect and acknowledgment from the people who see themselves as the gatekeepers of modernity, modern life and institutions.

The illness narratives of Altan and Abdullah are striking examples of how the Turkish cancer patients position themselves vis-à-vis Turkish modernity and how their socio-economic background informs their illness experiences and the quality of health care they receive. The recent historical changes in Turkish society affected the close association between modernity and health care system, and they affected the physical and social space in İstanbul, as illustrated in the development of the Güvercin and Okmeydanı neighborhoods. Those two developments affected the illness experiences of the cancer patients to the extent that Altan felt like "a brother" of health care providers, whereas Abdullah felt completely excluded or alienated by them as an "ignorant villager." The other cancer patients' illness narratives I collected fall in between the extreme cases of Abdullah and Altan, but they also reveal different aspects of the interaction between Turkish modernity and medical realm. I will discuss those issues, which constitute the basis of my ethnographic research and analysis, in the following chapters. In the next

chapter, I review the social science literature mainly on illness narratives and experience, which enabled me to construct the theoretical framework of my dissertation.

## Chapter 2

### Explaining Illness through a Social Science Perspective

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

(Susan Sontag, *Illness as Metaphor*, 1977)

The social science literature on health and illness informed both the theoretical framework and methodology of my dissertation. The oral and written illness narratives of cancer patients help me to understand how the patients give meaning to their illness experience and to evaluate the popular and medical views on cancer and cancer patients. As I discussed in Chapter 1, the patients' socio-economic background and position vis-à-vis Turkish modernity play an important role in shaping their illness experiences and narratives. My dissertation also takes into account how the social and economic inequalities influence the cancer patients' illness experience, as well as popular social and cultural conceptions of cancer. Therefore, I aim at covering the larger social, political and economic issues around cancer and cancer patients in Turkey, as well as investigating the illness experiences and cultural construction of illness narratives that reflect these experiences. The larger issues include the inequalities in the health realm, especially in terms of having access to adequate health care services and enjoying more open, less hierarchical interactions with health care providers. In order to study these

issues, which operate both at micro and macro levels, I combine a discursive-interpretive approach with a political-economy approach to the anthropology of health and illness.

The discursive-interpretive approach is particularly valuable in investigating the social and economic inequalities that inform cancer patients' illness experiences, since these inequalities also take place in the everyday interactions between patients and health care providers. The illness narratives reveal the quality of patients' lives with cancer, including how they experience and respond to the inequalities during treatment, as well as their culturally specific views on their illness, health and the body. Those views and the medical conception of cancer often exclude each other, since most patients and health care providers argue that the former belongs to the personal and psychological realm of superstitious "beliefs," whereas the latter is a product of modern science. I investigate the subjectivity of the patients' experience of their illness through an analysis of the cancer narratives, which also provide a critical reading of Turkish modernity as it is reflected in the medical realm. In order to study those issues from multiple angles, I also benefit from the political-economy approach, which takes account of the larger historical, political and economic processes. Therefore, I adopt the discursive-interpretive approach in my main analysis of illness narratives, and I will combine this with the political-economy approach in studying the political and social matters that inform those narratives.

Although my research focuses on the cancer and cancer patients in the 2000s, it also has an important historical background, since illness experiences and narratives of today are informed by the processes of Turkish modernization and the introduction of biomedical institutions in the 19<sup>th</sup> century. The ways in which the biomedical views and

practices are introduced in the Middle East shaped the problematic interaction of those views and practices with local views and practices concerning health and illness. As I discussed in Chapter 1, the earlier generations of doctors were the pioneers of Turkish modernity, and the health care providers' definitions of "good" and "patients" have thus often had an ideological and political aspect. Recent historical works which investigate the introduction of Western biomedicine in different places such as India, Africa, and Middle East helped me to study how the discriminating processes of the past affects today's inequalities in illness experiences.

I also consider the inequalities that the Turkish cancer patients experience in light of the WHO's rather abstract and idealistic statements that every human being should have the highest attainable standard of health care and that biomedicine should co-exist peacefully with other health systems. The statements of the WHO are often invalid and inapplicable when they are applied to a particular cultural context. The WHO's statements also focus on present and future, rather than the past, and therefore they do not take into account the historical roots of the health problems which led to the formulations of such statements. As I discussed in the first Chapter, the introduction of Western medicine in Turkey in the 19<sup>th</sup> century has led to the association between modernity and medicine, and that association still informs the contemporary power struggles in the interactions between patients and health care providers (Dole, 2004).

The first section of this chapter focuses on the criticisms of biomedicine in terms of how it imposes certain conceptions of health and illness and how it produces and reproduces local, national and global inequalities. The next section discusses the studies on the patient's perspective, which focuses on how the patients experience and give meaning to their illnesses, and how cultural and medical conceptions of health and

illness play a role in shaping those processes. The last section covers the literature on health and illness issues in the Middle East, and in Turkey in particular, with a focus on how that literature can be related to the general social science literature on health and illness.

**The Critique of Biomedicine:** Biomedicine is far from being a uniform medical system, since biomedical discourse and practices change through time and place. Arthur Kleinman (1995) explains that biomedicine is necessarily plural and heterogeneous, since local medical views and norms strongly influence it, and biomedical doctors often coexist with local healers. However, he also argues that despite its heterogeneity, “there is something special about biomedicine and its Western roots...which decisively distinguishes it from most other healing systems,” such as Chinese and Ayurvedic medicines. It is a product of an over-arching discourse regarding which problems should be defined as a disease and how an ideal patient should behave in order to overcome a disease. In doing so, biomedicine excludes other health systems and views on health and illness. Biomedical principles assume the priority of universal science, technology, rationality and experimentation over the cultural conceptions and “beliefs” of health and illness in particular societies. However, several critical medical anthropologists questioned this view of medicine as universal and argued that “biomedicine is itself a cultural construction,” and, besides biological factors, “certain cultural assumptions about causality and normality” and cognitive categories also inform biomedical scientists to define and categorize diseases. Accordingly, “the practice of biomedicine varies according to local traditions” (Sargent& Johnson, 1996: pg.185).

In Turkey, where modern medicine and sciences play a pivotal role in defining modernity and differentiating it from what is non-modern, the boundary between scientific knowledge and “cultural beliefs” are even thicker and more ideological in the sense that patients are categorized as “good” and “bad,” based on their affinity with science and “modernity”<sup>16</sup>. Accordingly, I explore how the words such as science, reason, and research are used to categorize patients, medical staff and institutions and practices as “good” and “bad,” both by the concerned patients and medical staff.

Kleinman (1995) contends that biomedicine differs from other medical systems “by its extreme insistence on materialism as the grounds of knowledge.” Biomedical scientists explain the occurrence of diseases often with a single cause, and they are committed to a view of nature, which excludes the teleological, spiritual and irrational. Accordingly, nature is a physical entity that can be understood and explained thoroughly *only* by the scientists. Nature is the “bedrock of truth,” which psychological, social and moral and so many other “superficial layers” cover and disguise. Kleinman interprets this view of biomedicine as radically reductionist and ultimately dehumanizing, since it underestimates human experience and the meaning human beings attribute to their experiences. Biomedical doctors view the sick person’s illness narrative as an “untrustworthy story,” which should ultimately be replaced by the medical facts and data that are obtained as a result of medical tests. In contrast, Kleinman advocates for studying illness narratives in order to learn the patients’ perspective, which is not represented adequately in the medical realm and in the social conception of illnesses.

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<sup>16</sup> The doctors, whom I talked during my fieldwork research, often described the “bad” or “problematic patients” who “dared to talk about their superstitious beliefs with health care providers, and did not show the adequate respect and attention to the health care providers’ scientific explanations. In contrast, the “good” or “conscientious” patients, who were in minority, “spoke the same language” with them, asked scientific questions on their illness and fully complied with their treatment.

This is also valid for cancer in Turkey, as the most visible and talked about illness in the society. Most health care providers tend to overlook the patients' own explanations of why they had cancer or possible treatment methods as "merely speculations" or "superstitious beliefs," which do not have anything to do with science. Similarly, as I will discuss in the next chapter, there is a considerable gap between the medical and social conceptions of cancer, especially in the explanations of the recent increase in cancer rates in Turkey.

In his book "Illness Narratives: Suffering, Healing and the Human Condition," Kleinman (1988) differentiates "illness," which include people's efforts to give meaning to their disease and cope with it, from "disease," which is predominantly defined as a universal, neutral and biological disorder in biomedicine. Similar to Kleinman's differentiation of disease and illness, I noticed that especially elderly patients prefer to use a more formal and euphemistic word for their cancer, *rahatsızlık*, which means discomfort, a more experiential term, instead of *hastalık* which corresponds to disease. Seven patients I interviewed preferred the word *rahatsızlık*, and they were all in the age group of 56-75. Compared to *hastalık*, *rahatsızlık* also corresponds to minor health problems, which often do not require a hospital visit. On the other hand, Gülsüm, a breast cancer patient in her fifties, explained that *hastalık* is a very "cold word," which directly reminded her of "hospital," (*hastahane*, the word for hospital, literally means the house for sick people). She also believes that the word *hasta* is used to exclude the sick people from the other "normal and healthy people," since it is also used for all the biological and mental diseases. She finds *rahatsız* more humane, since it also refers to the discomfort that both healthy and sick people may experience.

Among the health care providers, only one doctor at Güvercin used that word, especially in his interactions with his elderly patients. Although that doctor was in his early forties, he explained that he liked “old Turkish, which is full of Arabic and Persian words” much better than “today’s made-up Turkish,” since it sounded more polite and formal. However, several doctors prefer to use *hastalık* instead of *rahatsızlık*, because of the direct connection between the words *hastalık* and *hastahane*, since that connection conveys the message that people with a disease take that disease seriously and should visit a hospital, instead of trying to cure it by themselves or with the help of alternative, local healers. That message emphasizes the hegemonic view of biomedicine, and it also fits into the doctors’ modernist views. The medical staff’s preference of the word *hastalık* (disease) also indicates their political position and views about how to interact with patients and how to inculcate “correct” health behaviors. Therefore, *hastalık* (disease), as it used by the Turkish medical staff, is not a neutral, merely biologically defined word, as Kleinman claimed, since it is informed by how the medical staff views the patients. *Hastalık* and *rahatsızlık* are both cultural constructions which inform not only the lay people but also health care providers, and thus they affect the Turkish biomedical discourse and practice. Similar to the other cultural constructions that I will discuss here, the differentiation between *hastalık* and *rahatsızlık* is a local and particular aspect of biomedicine in Turkey, which indicates how linguistic and cultural aspects inform the definition and categorization of diseases. (Sargent& Johnson, 1996).

**Medicalization and Inequalities:** Kleinman relates the dehumanization in biomedicine to the professionalization and commodification of health care, which is considered to be a product “that is advertised, marketed and sold” in the recent neoliberal

era. This view of health and health care attributes a particular economic and political aspect to biomedicine, and accordingly, biomedicine is seen as a product of the particular historical processes through which modernization in society, state power and authority and medicine have supported and strengthened one another. As a result, several problems such as alcoholism, drug abuse, homelessness and violence, which were seen as political and social conditions, are now defined as health or mental health problems that can only be solved through biomedicine. In the medicalized societies, medicine has gained a political and legal power, with a new mission of creating “healthy societies,” in accord with the norms and values of biomedicine. In the Turkish context, the processes of professionalization of health care providers and medicalization of the society started in the 19<sup>th</sup> century, and they played a pivotal role in creating a new nation with the foundation of the Turkish Republic in 1923. Accordingly, the doctors’ job was idealized as a “selfless mission” to improve the society in social and medical terms, and a public service, which should benefit every citizen. The commodification started with the privatization of health care services in the 1990s, more than hundred years after the professionalization of medicine, and has now harmed the professional solidarity, public prestige and authority of health care providers to a large extent (Sanal, 2004). In the case of cancer, for example, which has one of the most expensive treatments in Turkey, most patients often had problems in trusting their doctors’ prescription of certain drugs and suggestions of further tests. For instance, Yılmaz, a lung cancer patient and active union member, argued that the doctors had special contracts with drug companies, and that they always have to suggest one particular drug, which was produced by that company to all the cancer patients. However, he added that the same drug may not be as effective for

everyone or even may be harmful for some cancer patients, depending on “their age and other physical conditions.”

The commodification of the health care services has also produced conflicts among the “bad, selfish” doctors, who prioritized their economic interests, and “good, selfless” doctors, who still have the mission of “healing the nation” (Sanal, 2004). Accordingly, the social image of doctors is also changing, from that of politically powerful people with a sacred profession to economically powerful people whose job is beneficial mainly for themselves. The role of biomedicine thus extends far beyond its medical role of healing people and achieving scientific developments, since it also reflects and reproduces the social and political context in which it operates. The way biomedicine produces and reproduces inequalities in a particular society affects who becomes sick and who stays healthy, how the sick people are treated, and how their illnesses are conceptualized in the medical realm and in that society in general. In Turkey, major illnesses, such as cancer, are largely associated with poor, uneducated people who lack conscientiousness (*bilinçsiz*<sup>17</sup>), as one doctor at SSK hospital told me: “In this oncology section, most patients whom you will see would be ignorant, uneducated and *bilinçsiz* patients. The others, who are educated and smart people, just know how to protect their health, and even if they have cancer, it would be an early stage one, which does not require a huge medical effort to cure, since they care for their health. They know that cancer is frequently seen and highly dangerous, and come to see a doctor as soon as they detect something abnormal in their health or body. Therefore, they quickly recover, without the need of endless sets of chemotherapy or radiotherapy. In contrast,

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<sup>17</sup> Conscientious (*bilinçli*) patients and patients who lack conscientiousness (*bilinçsiz*) are often used by the health care providers to categorize good and bad patients.

the poor and uneducated people may not notice or pay attention to a huge tumor in their body for months.” Similar to *hastalık* and *rahatsızlık*, *bilinçli* and *bilinçsiz* are also common cultural constructions that shape Turkish biomedical discourse and practice in a particular way, and that inform how the health care providers view their patients and how they interact with them. The categorization of *bilinçli* and *bilinçsiz* patients also implies that the medicalization is not yet complete in Turkish society, according to health care providers who often have doubts about the *bilinçsiz* patients’ compliance with their medical treatment.

*Bilinç*, being a relatively new word, has the same root (*bil*) with the words *bilgi* (knowledge) and *bilmek* (to know), and thus it is associated with having a right body of knowledge and being thoroughly aware of a phenomenon. The word *bilinçli* (conscientious) and *bilinçsiz* (lacking conscientiousness) are *also* used in a normative way to describe the “right” or “correct” and “wrong” behaviors and choices, such as the doctor’s quote suggests. Besides being a typical example of medical elitism, that quote also shows how that the doctor ignores the connection between inequalities and illness, by reducing the issue of access to health care to the individual choices of *bilinçli* and *bilinçsiz* patients. However, the social, political and economic inequalities among the patients also influence their health behaviors and illness experiences.

In order to study how the inequalities among the cancer patients are operated and reproduced, we first have to look at the historical roots of the elitist categorizations of patients in Turkey, which dates back to the introduction of Western medicine in the Middle East in the 19<sup>th</sup> century. Several medical anthropologists also questioned the terms compliance and non-compliance with respect to the social, political and economic factors that affect patients’ seeking medical care in different countries, such as having a

health insurance, experiencing discrimination in the hospitals, and understanding medical bureaucracy (Baer et al., 1997). Non-compliance is also a problem that health care providers at SSK often talk about with respect to *bilinçsiz* patients who “do not fully believe in the power and authority of modern medicine.” According to those health care providers, patients often quit their medical treatment before they are completely cured and resort to complementary or alternative medical treatments without consulting to their doctors. However, my research indicates that cancer patients do their best to fully comply with their treatment, despite the problems that they experience in the hospitals. During my research, I did not meet or hear of any patient who quit his or her medical treatment, which made me convinced that non-compliance is an issue for some health care providers rather than for the patients whether they are *bilinçli* or not.

**Critical Perspectives on the History of Medicine:** The perspective of the studies on the history of Western medicine changed considerably in the 1980s, as a result of the theoretical debates in the social sciences and humanities. Before the 1980s, Western anthropologists, such as Victor Turner, focused on different views and practices concerning health and illness in different societies, rather than on biomedicine in the West or in other societies, and explored the connections between medicine and belief systems in those non-Western societies. They studied the effect of “folk beliefs” on health and traditional healing methods as a part of religious or spiritual domain (Good, 1994). They differentiated the local healing systems from biomedicine, which was assumed to be neutral, universal, scientific knowledge, free from political interests and cultural assumptions. Byron Good (1994) argues that early studies in medicine and social sciences were both based on a “culturally specific distinction between *knowledge* and

*belief.*” The beliefs of patients or people from a non-Western culture were often considered erroneous and different from the Western scientific knowledge, which was said to be attained through objective and empirical methods, as mentioned above.

However, many social scientists now argue all different medical systems, including biomedicine, are cultural products, shaped through their interactions with the social and cultural conceptions and institutions in different places (Good, 1994). This view has been widely accepted among social scientists since the 1980s, thanks to the critical studies on colonialism and Orientalism and their influence on the social studies of health and illness. However, those arguments are rarely reflected in the writings of social and medical scientists who write about the introduction of biomedicine in the Ottoman Empire and Turkey. The scholars often evaluate the institutional establishment of biomedicine throughout the whole country as a precondition of becoming a modern nation (Yıldırım, 2004). Having an uncritical perspective, they are also misled in their evaluation of *current* ideological relations between biomedicine and other health views and practices. As a result, they differentiate biomedicine and other health views and practices in Turkey in the same way as that the early social scientists once did, and think that the latter belongs to the frozen world of “tradition,” which has no connection to modernity and modern world. The studies that adopt a critical perspective on the history of biomedicine, particularly on its introduction to the non-Western contexts, will help me to adopt a more nuanced approach on the history of “biomedicine” in Turkey, and current interactions between biomedicine and other health practices (Gallagher, 1983; Chandavarkar, 1992; Comaroff, 1993; Fahmy, 1998).

The social sciences experienced a major shift in the 1980s, which also helped medical anthropology to adopt a more critical perspective on the history of biomedicine

and its interactions with other medical systems. Postmodern and postcolonial perspectives became prevalent in social sciences in the 1980s and 1990s and they have led to a reformation of anthropology as a discipline. Most anthropologists have adopted a self-reflexive approach and began to question the historical roots, current characteristics, and the social institutions of Western modernity. They developed a critical view of modernist views and practices, including their historical development in the West, as well as in other parts of the world, through the direct and indirect ways of colonization. Similarly, medical anthropologists<sup>18</sup> developed a critical perspective on biomedical knowledge and practices, as well as on how it is introduced and institutionalized in different societies.

The authors who subscribe to the critical perspective in studying the history of medicine indicate how the collaboration of medical and political authorities have served to maintain, reproduce or increase existing political, social and cultural inequalities (Ranger& Slack, 1990; Rosenberg, 1992). Several anthropologists question the claims of biomedical discourse of bringing positive sciences and modernity to the “non-modern” societies in order to heal their medical and social problems, and focus on the collaboration between biomedicine and colonialism in those societies. They discuss how the biomedical discourses and practices colonized people, legitimized the political and cultural discrimination against them, and helped to regulate and control the colonies such as Egypt, Tunisia, Africa and India (Gallagher, 1983; Comaroff, 1993; Chandavarkar, 1992; Fahmy, 1998). They show how an explanation of what causes a disease, such as plague or syphilis, can serve to stigmatize a group of people, and how the health care

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<sup>3</sup>Until the late 1990s, “medical anthropology” was the commonly accepted name of the subfield, which focuses on health and illness. However, the term “medical” was criticized as a part of the efforts to emphasize the social science perspective of the subfield. As a result, many anthropologists preferred “anthropology of health and illness” in the later years. This review will reflect that change in terminology (Lock& Gordon, 1988).

providers and scientists treat patients from different socio-economic backgrounds differently. The medical schools and hospitals were concentrated in the main cities of those countries, and prioritized the health of European colonizers and the “indigenous elite” who had close economic and social ties with the Europeans.

Following the Foucauldian paradigm, some of them contend that modern societies are regulated and governed through rigorous recording of births, deaths and major diseases, new rules of hygiene and vaccination for medical and political purposes, so that major aspects of people’s lives are known to the governments and ruling elite. Foucault’s view of power and knowledge, (1980), led these social scientists to focus on new realms and institutions, such as education, health, hospitals, schools, courts and prisons in order to study how power and power struggles operate through having control over knowledge in everyday life. These studies are based on a broader conception of power than narrower and classical political and economic views of power<sup>19</sup>, and they analyze how power operates at a discursive level as well as its more obvious manifestations (Comaroff, 1993; Chandavarkar, 1992; Fahmy, 1998). The discursive analysis is also helpful in studying how social and medical conceptions of particular diseases and doctor-patient interactions create and reproduce inequalities between healthy and sick people as well as among the patients who have regular interactions with health care providers.

These types of inequalities are reflected rarely in the limited statistics on cancer in Turkey and in health reports of cancer foundations and Ministry of health, since they do not include data on the patients’ socio-economic background. However oral and written illness narratives of cancer patients reveal these inequalities quite often. The sources such

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<sup>19</sup> Here, I include the studies on power, which focus on the acts and strategies of politicians and political parties to come into power and to maintain their power by ruling successfully the nation, or on the economic class-based thoughts and actions in particular societies.

as doctors' autobiographies and history of Turkish medicine also indicate the historical roots of those inequalities, when they are read through the critical perspective on the history of biomedicine. As I discussed in Chapter 1, although Turkey was not colonized in political terms, it showed similarities to the above-mentioned colonized countries in the sense that most biomedical institutions were founded in the main cities by European doctors who were invited by the Ottoman Sultans in the 19<sup>th</sup> century. The earlier generations of Turkish doctors, who were educated by the European doctors, internalized the mission to modernize the nation not only in medical, but also in political and social terms. That was only possible if they were the sole authority to define who is ill, who is sick, and how the sick people should be treated, as well as indicating how they should cooperate with the political authorities in terms of stigmatizing traditional elements in the society and working to eliminate them. That mission required the imposition of the biomedical discourse and practices, as well as the principles of Turkish modernization, with a top-down approach, and it can also be considered an "internal colonialism," as I discussed in Chapter 1.

The imposition of biomedical discourse and practices can be problematic in the case of cancer treatment, since doctors often disagree with each other about the effective treatment methods, as eleven patients I interviewed illustrated in their illness narratives. Biomedical discourses and practices also change over time, according to the new developments on health and illness issues. For instance, the recent increase in cancer rates and mortality rates due to cancer in Turkey have led the doctors to have a more radical attitude towards cancer treatment, similar to that of doctors in the U.S. (Payer, 1996). One doctor at SSK also explained that the doctors there have applied more radical surgical procedures, such as mastectomy rather than lumpectomy since the 1990s, in

order to reduce the risk of metastasis and increase the chances that the breast cancer patients will live for five years or more. The changes in biomedical discourse and practices over time, and the disagreements among the medical staff, also confuse the patients who often share their illness narratives and compare their treatments with each other

Biomedical discourse and practices also vary in different countries, since they are informed by the social and cultural conceptions of health and illness and the state's political and economic agenda. This is especially valid for cancer, because the results of the medical research on cancer are still debated among health scientists and there are several unknown issues about the causes and treatment of cancer. For instance, Lynn Payer (1996) notes that French doctors are often reluctant to perform mastectomy on their breast cancer patients because of their respect for the patients' "aesthetic, sexual, and psychological concerns," in contrast to the American doctors who believe in mastectomy and prioritize the assumption that a 'woman's life is more important than her breast.'" Payer also says that the attitude of American doctors stems from the general belief in radical intervention in the American medicine, and that it requires "doing as many high-tech tests as possible," even if they cause a "steep increase in health care costs." On the other hand, British and Canadian doctors have a more cautious attitude about the high-tech tests and radical interventions, because of economic concerns and lack of adequate research data (Payer, 1996).

As noted above, Turkish doctors recently prefer mastectomy over lumpectomy for the breast cancer patients, since they believe that the former is more effective. Moreover, given the increase in mortality rates due to cancer in Turkey, they prioritize "saving lives" over their patients' aesthetic and psychological concerns. However, Turkish doctors are

reluctant to operate on lung cancer patients and explain their reluctance that the operation is risky, since their tumor is close to the heart. I believe the fact that heart diseases cause the highest mortality rates in Turkey also informs the cautious attitude of doctors, who, otherwise believe in “radical intervention,” similar to American doctors. The cancer patients I interviewed often complained about the fact that their doctors prescribed “extra” chemotherapy or radiotherapy sessions “just to be on the safe-side,” after they were declared as cancer-free. They also complained about the number of medical tests that they had, since their doctors “did not even look carefully at some of them.” One doctor at SSK explained that the Turkish doctors indeed believe in “radical intervention,” since most cancer patients came to the hospital late, when their cancer is developed and spread to their body to a dangerous extent. She said that, as doctors, they do everything that they can, and then some more, to treat their patients, since they do not trust that the patients will take care of their health adequately once they are cancer-free, even if there is a risk of recurrence.

As the quote suggests, the Turkish doctors’ belief in radical intervention also stems from their lack of trust in their patients, especially in the case of “bad” ones, “who do not know how to take care of their health.” This problem and the categorization of good and bad patients also stem from historical developments in Turkish medicine. The biomedical health care services prioritized the urban elite’s health problems in the 19<sup>th</sup> century, and that eventually led to a chronic problem of inequality in the distribution of health care services in urban and rural areas. That problem, which is still not solved today, despite considerable improvements in the 1930s and 1960s, is also one of the reasons why several doctors at SSK complained about the “crowds of ignorant villagers,” who visit SSK hospital in Okmeydanı on a daily basis. Those doctors used those words

unapologetically to describe the patients with a rural background and blamed them for not knowing how to take care of themselves.

The Turkish doctors' idealistic mission of healing the social and medical problems of the whole nation, has become anachronistic and transformed into the burdensome task of taking care of the patients "who often made themselves sick," when faced with the actual health problems of the recent decades. That transformation is also reflected in the doctor-patient interactions, which reflects the conflicts between the medical discourse on cancer and the patients' own views on their illness. Those conflicts are also informed by the socio-economic inequalities in the society, since they define the quality of health care services that the patients benefit from, in terms of dealing with the hospital bureaucracy and interactions with health care providers. The social, political and economic inequalities, and how they inform the patients' illness experiences is one of the most common topics in the anthropology of health and illness. In the next section, I will discuss different perspectives in that literature and relate my research and analysis to those perspectives.

**Illness and Inequalities:** The inequalities and the illness are related to each other in many ways, and they reproduce each other, since the sick people are treated as the "other," especially when they have a major or chronic illness, such as cancer. The popular and medical discourses on sick people inform each other, and, as a result those people are stigmatized and marginalized to a large extent. In her book, "Illness as Metaphor" (1977), Sontag challenges the assumption that biomedicine is culturally neutral. According to Sontag, the health care providers are influenced by the popular metaphors of diseases, such as the war metaphor, in developing their own views on

diseases and shaping their attitude towards their patients. The people with tuberculosis (TB) or cancer are marginalized and stigmatized in the medical realm and in their society through the use of those metaphors, according to which the words TB and cancer become a taboo to mention even in the hospital context. Those illnesses are then regarded as a “disgrace to hide.”

Sontag argues against the “medical paternalism” which reproduces those metaphors and the mythic character of TB and cancer, and suggests that the conceptions of disease should be liberated and purified from metaphors and metaphoric thinking. Byron Good (1994), however, points out the problematic aspect of Sontag’s “desire to do away with metaphors,” which is in conflict with her criticism of science as being neutral and isolated from cultural influences. Good argues that this aim “reproduces the Enlightenment ideal of a culture-free representation of disease, disease as an objective reality.” Later on, possibly as a result of those criticisms, Sontag (1989) clarifies her stance on illness metaphors in her book “AIDS and its metaphors,” where she contends that AIDS reinforced the use of military metaphors in medicine. According to Sontag, the war against cancer at an individual and societal level is reincarnated as a war against AIDS, and this type of military metaphor makes people with cancer or AIDS “suffer needlessly” because of the particular meanings attributed to these diseases. They feel isolated and estranged from the rest of their society, which adds to their burden of psychological and social problems related to their disease, which they view as a punishment for something that they did wrong, or to a particular character flaw that separates them from healthy people. Sontag notes that she is against the use of such metaphors, especially the military ones, which further disempower the people with cancer or AIDS.

As I will discuss further in the next chapter, the war metaphor is often used in Turkey, in the official and medical discourse on cancer and other major illnesses, such as TB and in malaria, and even the organizations that are concerned about eliminating those illnesses have names such as “War against Cancer” and “War against TB.” The use of war metaphors as such dates back to 1930s, when the political and medical authorities collaborated in their efforts to create a new and healthy nation for the new republic after a series of wars that ended with the Turkish independence war (1920-1923). The military metaphor can be also related to the pivotal social and political role that the first modern medical school, which was a military one, played in bringing modernity and good health to the Turkish society in the 19<sup>th</sup> and early 20<sup>th</sup> centuries. Possibly because of those historical connections the health care providers and policy makers in the Ministry of Health use the war metaphor without questioning it, and have a top-down approach about how the society should view the diseases and how people should act when they are ill. A public relations officer in the “War against Cancer Section” in the Ministry of Health explained that health care providers cannot fight to eradicate cancer throughout the whole country by themselves, and they need the full support of the policy-makers and collaboration of citizens in their fight. He described his job as propagating the correct knowledge on cancer and promoting the correct attitude that the cancer patients and their relatives should have at a national level: “We conduct a wholesale fight against cancer and try to reach all 70 million people, including the ones who are in the remotest corners of the country and rarely see a doctor. When we have such a big task, we can rarely be socially or culturally specific or evaluate the impact of our efforts in social and cultural terms. We just say, ‘go see a doctor if you have such and such symptoms’ or warn people against cancer inducing habits, such as smoking and drinking. We publish thousands of

posters, brochures and booklets, and distribute to the health care institutions of the whole country. Lately, we started to offer possible scenarios about cancer patients to the popular TV series, and I believe that became highly influential.”

Another policy maker added that they do their best in fighting cancer, but that fight should also be fought at an individual level, since all the citizens should feel responsible in avoiding cancer or benefiting from the right medical treatment. Christopher Dole (2004) explains that the policy makers view individual’s health as closely connected to the nation’s health in the early decades of the Republic, where the eradication of epidemics, such as malaria and TB were crucial public and political issues. Accordingly, when people behaved irresponsibly in maintaining their health, that will affect the health statistics of the whole country, which also indicated its level of development and modernization. Therefore, the state and policy-makers were directly responsible in determining the “strategies and tactics” in the wars against major diseases, and the people should fully obey those tactics and strategies. The political and medical discourse on war against cancer echoes the views and arguments used in fighting against those epidemics more than half a century ago. However, how the patients view and experience their illness, and how they are possibly robbed of their voice and disempowered by war metaphor are not trivial issues, which social scientists should investigate, as one of the policy-makers in the Ministry of Health suggested.

My thesis combines two main perspectives, interpretive and political economy approaches (Good, 1994). Social scientists who subscribe to the discursive- interpretive approach note that biomedicine falls short of accommodating the ill people’s uncertainty, anxiety, stigmatization and isolation, through its concentration on biological aspects of illness. Interpretive approaches have benefited from semantics, hermeneutics,

phenomenology, linguistic and narrative analysis, in order to investigate the social and cultural processes, through which the patients come to see themselves as the “other.” They also focus on the patients’ efforts to give a particular meaning to their illness experience and how the social and cultural background of the patients, as well as the popular and medical conceptions of those illnesses, shapes those efforts. Byron Good (1994) calls this approach the “meaning centered tradition,” since it goes beyond the narrowly focused health belief studies and engage “in wide-ranging investigations of symbolic structures and processes associated with illness in popular culture and various therapeutic traditions.”

Other scholars, taking a political economy perspective, have criticized biomedicine, in terms of maintaining and reproducing the unequal political and economic relations, despite the biomedical scientists’ claims about the biomedicine’s political and social neutrality. Byron Good (1994) calls this group “critical medical anthropologists.” They argue that biomedical knowledge and practices do not take place in a vacuum, and they have a close interaction with the political and economic inequalities in the society. They study the role of political and economic power in health care relationships and transactions, and the unequal distribution of health care services at local, national and global levels (Baer et al. 1997). They also investigate how those inequalities influence the illness experience of the patients with different socio-economic backgrounds, particularly the ones with the disadvantaged background. They indicate that the social groups with a disadvantageous socio-economic background have higher levels of mortality and morbidity, since they have more serious health problems and have difficulties in receiving appropriate health care.

Vinh-Kim Nguyen and Karin Peschard (2003), who review the recent works which focus on illness and inequality from an anthropological perspective, indicate that these works help us to have a broader and deeper understanding of the correlation between high levels of socio-economic inequality and worsened health outcomes. Anthropological studies look for possible reasons for this correlation, such as “diminished social cohesion, psychobiological pathways or the material environment.” Nguyen and Peschard argue that affliction is embodied in the current social hierarchies within and among societies, and the variances in disease rates, and that morbidity and mortality are reflections of this chronic problem. The authors call this the “illness poverty trap,” since the violence of inequality “will continue to spiral as the exclusion of the poorer societies worsens their health” in an era of “neoliberal health economy.” (ibid: 464)

This problem also shapes the processes of commodification of the body in different ways in different societies, and especially in the trafficking of body parts and organs. The vicious circle of illness and poverty is far from being a merely political and economic issue, since it also has to do with the social and cultural conceptions of illness and poverty, which also shape the social policies on health and sick people. For instance, the rapid privatization in the medical realm in Turkey in the 1990s focused on providing “a five star hotel service” to the upper class elite and establishing medical tourism by attracting rich patients from nearby countries, at the expense of the poorer and sicker citizens. The privatization process has increased the gap between the rich and poor in terms of general health condition and health care access, as well as between the urban and rural areas in terms of the distribution of health care facilities. That processes also led to shrinkage in the role of the state in creating and maintaining a healthy nation, and the citizens’ right to health has become a matter of individual responsibility of staying

healthy. When poor people with the state insurance or “green card” become sick, policy makers often see them as an additional burden to the state, since it has to cover the necessary treatment and medicine.

Considering the complexity of health and illness issues and the interaction among political, economic, cultural and social dynamics in shaping those issues, anthropologists have recently combined the discursive-interpretive and political economy approaches. They often study a particular locale in detail and, and by locating their ethnographic studies within a larger frame, they emphasized particular historical and political contexts in shaping different conceptions of health and illness (Lindenbaum & Lock, 1993; Farmer, 1999, 2003). According to those studies, the inequalities that influence the illness experiences and narratives of the patients do not only stem from tangible political and economic reasons, but also social and cultural dynamics, which serves to produce discourses and conceptions on illness that marginalize and discriminate against some patients.

Through the prism of this perspective, which acknowledges the multi-sidedness of health issues, medical anthropologists have also criticized the abstract conception of health that appears in the 1986 Declaration of World Health Organization (WHO). The declaration states that: “The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being.” The statement is a highly general and ambitious one because of its universal perspective, similar to the other human rights’ statements, which impose what is good and bad on every human being living in this world (Mann et al., 1999). Recent works show that many people do not have adequate access to even basic health care, because of political conflicts, economic difficulties and cultural discriminations (Farmer, 1999, 2003). Furthermore, studies indicate that people have

different criteria to describe their illness and well being, and their expectations from the health care services and institutions vary from one social context to the other. Therefore, the WHO statement is far from being a guarantor against the inequalities and discriminations in the health realm in particular social contexts. For instance, ten cancer patients, eight of whom had their treatments at SSK, said that they do not expect the doctors to provide psychological support for them, even if they needed it when they learned that they were diagnosed with cancer, or to talk about their illness and treatment in detail. The patients justified this by explaining that the doctors do not have time for such tasks and that they have to focus on examination and prescription of the necessary treatment. Five of those patients even said that they do their best in order not take the doctors' precious time.

In many countries, including Turkey, most health scientists and politicians believe in the statements of the WHO in theory, but they also point to the difficulties in their application because of the shortage of health care workers, their unequal distribution in the country and the inadequate infrastructure, as well more general political and economic problems of the country. Moreover, the difference between the medical and cultural conceptions of health, illness and the body also create problems in the interactions between medical authorities and lay people. That is especially valid for the statement of the WHO that the alternative or complementary medical systems should cooperate with biomedicine and they should be integrated to the main medical system in the country. Christopher Dole (2004) quotes a Turkish public health specialist who argued that Turkey is not “modern enough” to realize that collaboration and integration. The quote can be interpreted in accord with the tension between modern health care providers and “traditional healers” and the historical roots of that tension, and the mistrust of the former

towards the latter, which stem from the health care providers' modernist ideology. Many health care providers I interviewed believed that the patients benefit from the "traditional healers" out of despair, since they do not have access to the modern health care institutions, either because of economic or geographic reasons. However, those health care providers seem to ignore that numerous cancer patients are treated at the hospital *and* benefit from alternative and complementary health care methods at the same time, as 42 out of 50 cancer patients I interviewed did. Having an evolutionary view, they believe that when Turkey will be "modern enough" so every citizen would have an easy access to modern health care institutions. Accordingly, as a doctor at SSK hospital explained, "they can make a more conscientious choice" about whether to go to a modern doctor or a "traditional healer," and that the latter would be marginalized to a considerable extent. That argument and wish for the future, obviously do not fit into the WHO's vision of egalitarian interaction and cooperation between medical systems.

Several medical scientists and public health specialists refer to the fact that the recent increase in poverty and the gap between economic classes worsened the health conditions throughout the country more on a speculative level, because of the inadequacy of statistics. Those speculations are also informed by those scholars' political and ideological positions, and they are often the products of one-sided approach to the complex and multi-sided issues of health and illnesses. Considering those problems, I use the written and oral cancer narratives in order to argue that the inequalities that the Turkish cancer patients experience are related to social and cultural factors, as well as the economic ones. Although, having illness narratives as my main research method and tool of analysis makes me benefit more from the discursive-interpretive approach, I combine it with the political economy approach by using the few, general cancer statistics available

and other related data on cancer and cancer patients. The meaning-centered is also more useful for me in order to analyze the modernist discourse in terms of how it is internalized and reproduced in the medical treatment and how it influences patients' illness experiences. However, as I noted earlier, I will also benefit from the political-economy approach, which will help me to locate those illness experiences and narratives within their larger political, economic and social frame, and connect what is individual with the processes that take place at local, national and global levels.

**Illness Narratives:** Although the studies that focus on illness narratives are a part of the discursive-interpretive perspective, they have also created their own genre by combining their research with the theoretical arguments about narrative in psychology, political sciences and linguistics. The studies that discuss different ways of analyzing illness narratives are particularly useful for the theoretical framework of my dissertation, since they indicate how the narratives reflect the interaction of complex social, cultural and psychological dynamics. Arthur Kleinman is one of the pioneers in the study of illness narratives, which focus on human experiences of suffering from the symptoms and the disability brought on by illness. His book, "Illness Narratives" discusses what ill people often experience in coping with their illnesses and trying to give meaning to the social and psychological changes that their illness has caused (Kleinman, 1998). His work has led scholars to more readily associate illness with coping skills, psychological and social traumas, loss and disruption. That association is also recently challenged through the works, which developed a more nuanced approach towards illness narratives and how they are influenced by cultural codes and social values.

Cheryl Mattingly and Linda Garro (2000) contend that paying attention to the ways in which people construct their own illness narrative is crucial, since in producing an illness narrative, the ill people revise and reconstruct their identity and social position. They also re-establish a culture-specific sense of order, control and continuity after a disruption. Illness narratives also include a particular temporality, since they have a unique way of connecting the past times of “before the illness” to the present illness experience and to the hopes and expectations about the healing process in the future. The aspirations for being “normal,” healthy and fit again, getting rid of the “sick” label and role, shape this temporality to a large extent. Mattingly indicates that through illness narratives ill people build a bridge between individual and social or cultural realms, and what is private and public. According to Linda Hunt (2000) illness narratives “can become potent micro-political tools, re forging the disrupted identities of patients.” Hunt explains that chronic illness “can produce major disruptions to the core components of identity, such as social roles and relationships, and in these cases, illness narratives “hold the potential not only of articulating the disruptions experienced but also of reconfiguring one’s very social identity.” Through telling illness narratives, ill people influence how their illnesses and their selves are understood in the society, and they integrate their illness into the larger context of life. Therefore, the very ability to construct an illness narrative, which represents personal, bodily and social experiences brought about by the illness, and to convey it to a different “audience,” is empowering for the patients and crucial for their healing process (Mattingly and Garro, 2000).

This is also reflected in the illness narratives of several cancer patients who stressed that they do their best to be strong and keep their morale high as doctors told them to do. Eleven patients also said that they try to solve their problems related to cancer

“by themselves,” and six patients emphasized that they live their lives fully, as if they do not have cancer, besides having their regular cancer treatment. Although those explanations can be also seen as a part of the patients’ efforts to fit into the doctors’ category of “good patient,” by representing themselves as strong and independent, they also challenge the social conceptions of cancer and cancer patients in Turkey, including its close association with suffering and death. Therefore, by downplaying their psychological and social traumas, instead of trying to give a meaning to them as Kleinman suggested, those patients “re-establish a culture-specific sense of order, control and continuity.” Although this prevents the patients from acknowledging and sharing their problems with other people to a large extent, it also gives them a potential for empowerment, which is related to the way they challenged the common view of “weak cancer patient who suffers constantly.”<sup>20</sup>

Some of the studies on illness narratives also focus on the ways in which larger medical and cultural discourses on illness stifle patients’ own voice, through marginalizing and stigmatizing sick people with their over-arching explanations. The studies of illness narratives and metaphors point out that the biomedical discourse imposes a certain disposition and attitude to the ill people which they have to negotiate in order to find and articulate their own voice in shaping their illness narratives (Kleinman, 1995). However, ill people may gain the ability to challenge their portrayal as the “other” in the medical and popular discourses, through their illness narratives which redefine their position both in their immediate environment and society. The illness narrative is also a useful tool in analyzing what people experience when they become sick, how and what kind of meanings they attribute to their illnesses, and how medical and cultural

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<sup>20</sup> I will discuss this issue further in Chapters 5, 6 and 7.

conceptions of body, pain and illness play a role in these processes (Martin, 1987, 1994, Frank, 1995; Morris 1993, 2000; Greenhalgh, 2001).

In the following chapters, I will give examples of cultural and medical conceptions of cancer that differed from each other, with respect to discussions of what is a tumor, what is “bad water” and how those elements are connected to cancer, the connection between emotional stress and cancer, and whether cancer is an epidemic. Although these are the issues which cancer patients and doctors interpret differently, the patients may often overlook that difference and try to convey their own explanations as the scientifically and medically valid ones. Those explanations also led me to understand why the cancer patients I met at SSK and Güvercin hospitals were eager to tell their illness narratives, both to me and to each other, and to derive their own meaning from their illness experiences. As I will discuss in the following chapters, their narratives also helped them to portray themselves as the “good patients,” even though the health care providers may place them in the category of the “bad” or “problematic” patients.

The literature on illness narratives helps me to investigate how the personal, private and individual aspects of cancer patients’ illness narratives co-exist with the over-imposing cultural and medical conceptions of cancer in Turkey. In those narratives, the patients also relate their personal characteristics to the commonly accepted “cancer personality” of patients, and use that association for their own benefit. Through those narratives, I analyze how the cancer patients view and respond to the close association between cancer and death, and its conception as a taboo to the extent that mentioning the word “cancer” is avoided even in the hospital. The narratives also help me to study how the patients balance their trust in modern medicine with the uncertainties in the outcome of their medical treatment and the difficulties they experience in their social interactions

with the health care providers. Finally, I relate those narratives to the modernist ideology that is embedded in medical discourse and that informs the categorizations of “good” and “bad” patients. Through discussion of those topics, I analyze how the Turkish cancer patients find their own voice and reconfigure their identity, and contribute to the illness narrative literature cited above by providing an ethnographic example from Turkey. I also contend that the illness narratives in Turkey and in other countries of the Middle East have significant common elements in terms of how the social conceptions of health and diseases are informed by the efforts of modernization and nation building, and the role of medicine in those processes.

**Health and Illness in the Middle East:** Studies of health and illness in the Middle East are also informed by the main perspectives in medical anthropology. In accord with the chronic political and economic problems of the region, such as unstable governments and political regimes, high unemployment, poverty and inflation, those studies initially favored the political-economy perspective, and often included macro-level, quantitative research. Many social scientists studied how those political and economic problems interact with the demographic issues in the Middle Eastern societies, such as massive migration from rural areas to the big cities, rapid population increase and high infant mortality rates. They focused on the political and economic problems, such as lack of education of parents, poor living conditions of recent migrants and their difficulties in having access to the medical institutions, and they related those problems to the main health issues (Gürsoy, 1992; Tekçe et al, 1993; Obermeyer, 1995). However, a new generation of social scientists also explored the cultural and social meanings, as well as political and economic implications of demographic issues, such as strategies behind

forming a family, having and raising children. They include theoretical debates on power, authority and knowledge, and anthropological works that have a critical perspective on the history of modernization, nationalism, colonialism and post-colonial struggles. They also successfully combine the political-economy and discursive-interpretive perspectives by studying how the inequalities take place both through discourses and practices at local, national and global levels. Those studies focus on the political and military conflicts, such as the conflict between Israel and Palestine, and investigate how the demographical issues and people's life cycles are informed by those conflicts in cultural and political terms (Kahn, 2000; Weiss, 2001; Kanaaneh, 2002). The studies indicate that giving birth to and raising healthy and strong children became a symbolic act and political strategy, which aims at contributing to the existence and continuity of a contested community or a country.

Current anthropological works also question the Western political and cultural influence in the Middle East, and explore how the European-style governmentality and institutions are introduced through direct colonization or imposition due to asymmetrical power relations, as I discussed above (Fahmy, 1998). Some studies on the influence of Western colonialism in increasing health inequalities in the Middle East focus on how the opening of Western-style hospitals and medical schools in the big cities increased the inequality between urban and rural places in terms of access to medical services. They also explored how non-Muslim minorities had better access to these Western style institutions both as patients and as potential health care providers. They show how the cultural discourses and political practices support each other in order to establish the superiority of Western medicine and health care providers. For instance, the British and French officers commonly viewed medical education as “too complicated for natives,”

especially for the Muslim majority who do not know any Western language, and they were afraid that “the natives” could acquire dangerous ideas such as rebellion and mobilize against the colonial forces in Tunisia and Egypt. As a result, they discouraged the natives’ entrance to the medical schools through strict regulations and quotas, and the numbers of Egyptians and Tunisian doctors dropped considerably over the colonial period (Gallagher, 1983; Watts, 1997).

As I mentioned in Chapter 1, the studies on the introduction of biomedicine in the Middle East also focused on the historical association between medicine and modernity in that region. The ideas of nationalism, independence and modernism, imported from the West, are re-produced in the medical institutions and spread out to the rest of the society. In the 19<sup>th</sup> century, the introduction of mass printing technology in the Middle East helped the publishing and distribution of books, newspapers, pamphlets, which support the ideas mentioned above. Together with that printed material, the newly established Western-style schools also provided a base for the people who share such ideas to gather and mobilize against the Western colonial rule and Ottoman sultan whose rule is based on Islam. This reactionary group, which includes a considerable number of “native” medical school students, graduates and doctors, formed the new modern, secular and urban bourgeoisie and became the new ruling elite of the Middle Eastern countries after the demise of colonial rule and the Ottoman Empire (Hourani, 1992).

The post-colonial critique in the Middle East, initiated by Edward Said’s (1979) “Orientalism,” provides the theoretical framework largely based on Foucault’s view of power and knowledge. However, despite the influence of “Orientalism” on the Middle Eastern scholars, Said’s emphasis on the role of cultural representations in establishing power relations was initially overlooked by those scholars who focused instead on

political and economic discriminatory processes. The life of people with a disadvantaged background, such as women, people with a major disease, and people from ethnic groups who are in conflict with the state, has become a common topic for the social scientists (Pliskin, 1987; Morsy 1993). Social scientists have thus explored how people respond to the discriminatory practices in their everyday life and in health care. Social scientists who adopted a political-economy approach focused more on discriminatory political, legal and religious practices than cultural discourses. This tendency created an artificial boundary between those, mostly Middle Eastern, social scientists who study inequalities in the health care of their own countries from a political-economy perspective, and the other, mostly Western, social scientists who adopted a cultural-interpretive approach in studying health and illness issues in the Middle East. That boundary hindered both the collaboration between the Middle Eastern and Western social scientists who work on the issues of health and illness, and a combination of discursive-interpretive and political economy approaches in studying the contemporary inequalities in the health realm.

The latter group of social scientists, who hold a discursive-interpretive approach, deal more with various explanations of diseases that are informed by popular versions of Islam or by folk views and practices of medicine. They mostly study rural people without taking into account the larger political, social and economic context, which influences these villagers' illness experiences and narratives (Good, 1977; Good, 1994). For instance, Byron and Mary-Jo Delvecchio Good (1994) worked with a group of people with seizure disorders in a small town nearby Ankara, in order to examine "the role of narrative in the constitution of illness and illness experience." Most of these people are diagnosed as epileptic in the hospitals they visit, but they and their families hesitate to categorize their own "fainting spells" as such, and the stories they tell about their health

condition reflect their ambiguity about the nature of the illness. According to Byron Good “a typical cultural form or narrative structure” governs these stories, which often reflects the connection between the causes of disorder and emotional or spiritual powers in patients’ lives, such as a shocking moment in life that started the disorder.

The authors often quote the patients and their family members reporting their “long history of seeking medical care both from physicians and from religious healers.” The illness stories include accounts of how patients paid big sums of money to religious healers for a long time. One patient’s husband’s claims that a *hoca* (religious healer) built the second floor of his house with the money he gave him, and that doctors treat people “like animals” in the hospitals. However, the authors overlook the social, cultural and economic dynamics behind those claims and do not discuss the interactions between the patients and doctors or healers, since they mainly focus on how the disorder is defined, categorized and imposed in different therapeutic systems. They also do not take into account these people’s socio-economic background and how it is related to their illness stories, since they are primarily interested in the “semantic network” that is used to explain this disorder and that is informed by different therapeutic systems as well as folk or religious beliefs.

Studies on health and illness in the Middle East, which emerged in the recent years, have challenged the artificial boundary between studies that focus on inequalities and those with a strictly cultural perspective. They combine those two approaches, by taking into account the larger historical, political and social context of the countries where they conduct their research and analyzing how that larger context play a role in shaping daily experiences and individual narratives in particular settings. The combination of these two approaches helps social scientists to fully investigate the issues of health and

illness in all their complexity, by using a wide variety of research methods, such as archival research, media survey, statistical analysis, interviews and other qualitative methods. These studies, which I will focus on in the next sections, set an example for my own work, not only in terms of their theoretical perspective, but also for the research methods.

**The Problematic Interaction of Different Perspectives in Health Care:** Recent studies on health and illness in the Middle East, especially current analyses of health and illness in Israel and Turkey, deal with various debates among the biomedical scientists, health care providers, and how people with an illness play a role in these debates. They have a critical perspective on the history of medicine in the Middle East, with a focus on the introduction of biomedicine in the 19<sup>th</sup> century, and they also include how that historical process has influenced today's medical institutions in the region. Akile Gürsoy (1996) and Christopher Dole (2004) note that the historical association between Turkish modernity and biomedicine is still influential in maintaining a hierarchical and exclusive relation between biomedicine and other health views and practices. They focus on the cultural and historical aspects of biomedicine in Turkey, and on the interaction of biomedicine with the Turkish popular culture, media and the patients' perspective. They also benefit from the political-economy perspective, since they investigate the conflictual interactions between medical doctors and other, less institutionalized, healers, and relate the health views and practices of the Turkish people to their socio-economic background.

Christopher Dole (2004) explains how Turkey's health care system developed "as a prominent site for the articulation of the state's broader modernization project." He adds that as a result, many health care providers and lay people still define "formulations of

subjectivity and citizenship” in terms of whether the patients chose biomedical treatment or “traditional healing” systems which are associated with religious authority. Dole contends that because of the association between biomedicine and modernity, it is very hard to formally integrate complementary or alternative medical methods to the institutionalized biomedical health care system in Turkey, although this is one of the main strategies of the World Health Organization (WHO). Dole gives examples of the criticisms of secular Turkish people against the *üfürükçüs* (the religious authorities who heal people with their prayers and spiritual power in their breath), who “don’t rely on anything scientific” and who are threatening for the secular society and modern state. Similarly, a public health worker, mentioned by Dole, claims that Turkey is not yet modern enough to integrate “traditional medicine” into its health system when Dole explains his project and the aim of the WHO, as I discussed above.

The new generation of social scientists also focus on the current health problems which have become public issues and which are debated from different perspectives among politicians, health care providers and lay people. Aslihan Sanal (2004), who studies organ transplantation and trafficking in Turkey, and investigates how the ethical, social and economic aspects of this topic are discussed among the health care providers, the people who received a kidney, and in the media. She also writes about the legal aspects of organ transplantation according to which transplantations of organs from cadavers are illegal, but also mentions that the state fails to control that process, because of the privatization of medicine. Two hospitals managed to have such operations, by benefiting from the recent laws about the degrees of kinship, which also allows organ donations from the people who are emotionally close to the patients, and receiving money under the name of charity. The doctors who are involved in those “illegal” operations

legitimize what they are doing in humanistic and altruistic terms, by indicating that they save the lives of many people who badly need a kidney to survive. However, they are also criticized by the doctors who are also against the privatization process as prioritizing their and their hospital's economic interests, and by the media, who portray them as the vicious members of an international mafia in a rather sensational way. As a result, their image in the society and among patients ranges from that of "Organ mafia doctor" to "Robin Hood" and "hero" who rebel against the redundant laws and bureaucracies. Sanal also explores the strategies of patients in finding an organ and having the transplantation, which depends on their economic ability and conception of risks. Sanal's article successfully reveals the complexity of organ transplantation as a health problem and a public issue, since she deals with political, economic, legal and ethical aspects of that issue.

There are also some recent studies which fail to combine the political-economy and cultural-interpretive approaches or to reflect the complexity of health problems as public issues, although they claim to have a broader focus. Interestingly, two examples of such studies focus on cancer, which is one of the most socially visible illnesses, as well as being related to the most personal and individual aspects of people's lives. In Iman Hammady-Roushdy's (2004) articles on the debate about possible causes of the high cancer rates in two villages of Nevşehir, Turkey, the author describes the economic and social life in these villages and popular conceptions of risk related to cancer both among the villagers and medical scientists. Villagers view kinship, quality of air, humid stones and rocks (which are also used to make houses), and polluted food as possible causes for cancer, on the basis of family stories, memories of childhood, rumors and folk beliefs. Although those concepts are contested among the lay people, the debates about them are

sharper between two groups of medical scientists from different hospitals who also cannot agree on whether the high cancer rates are due to environmental or genetic reasons. In my own dissertation, I came across similar debates about the possible causes of the recent increase in cancer rates in Turkey, which also showed variations according to its particular regions, as I will discuss in Chapter 3.

The medical debates influence the villagers' conception and narratives of cancer, and the medical scientists' decisions about what caused cancer change the lives of villagers drastically. In the mid-1990s most residents of one of these villages emptied out their houses and moved to a newly built, smaller village nearby, when certain minerals in the rocks in the old location were thought to cause cancer. However, recent research showed that the same type of cancer (mesothelioma) is also seen in the second and third generations of people who migrated from these villages to Germany and Sweden, and the cause of these high cancer rates is considered to be genetic. Hammady- Roushdy, who also shares this opinion and worked with these scientists, collected cancer narratives of the villagers who live in Sweden and Germany for several decades. She notes that the villagers both in Turkey and Europe have a deep suspicion towards biomedical discourse and practices, especially biopsies and other operations, and do not want to be treated just as sick bodies or as a number given to them by the medical scientists. Three cancer patients, whom I interviewed, expressed a similar suspicion about being treated in the U.S. And in Europe, since the cancer centers there may treat the patients, who do not their language and their medical or bureaucratic system, as "guinea pigs," as I will discuss in Chapter 5.

The same theme of suspicion also exists in the article of Susan Sered and Ephraim Tabory (1999), who discuss the "treatment narratives" of Israeli female breast

cancer patients and their evaluation of the attitude of medical staff during their treatment. However, rather than talking about the larger social issues around cancer in Israel, or providing the socio-economic background of the cancer patients they interview, the authors focus on how the patients evaluate the medical staff according to the concepts of *yacha*. In the Jewish belief system *yacha* is a term that can be loosely translated as attention or attitude. Accordingly, the women with breast cancer differentiate good *yachas* of some medical staff who treat them “like humans” or “like real friends” from the bad *yachas* of others who treat them like numbers, machines or strangers. The authors argue that in telling their treatment narratives in various contexts these women use language “as a means of resisting the medical culture’s pattern of treating patients as “non-humans.” Neither Hammady-Roushdy nor Sereed and Tabory situate their ethnographic analysis into the larger political, social and economic context of Turkey and Israel respectively. Those authors, however, successfully show how the patients’ perspective and conception of illness are influenced by a large variety of factors, such as their interactions with health care providers, religion, and their conceptions of the environment and risk. The last two works of this section influenced my dissertation in terms of indicating the importance of the patients’ perspective and investigating how this perspective is informed by the medical views and practices, especially in the case of cancer patients who have to cope with so many ambiguities.

**Cultural Discrimination in the Health Realm:** As the last two examples show, the works of medical anthropology, which focus on biomedical discourse and practices in Israel and Turkey, show striking similarities. The similarities stem from the fact that the political and cultural processes of nation building interacted closely with the

introduction and development of modern medicine, especially in terms of assessment of citizenship and building social hierarchies in both countries. The ruling elite and intellectuals who shaped the nation-building processes in Israel and Turkey relied on scientific theories and research to define the social and cultural identity of a good citizen, which is also informed by the ethnic and religious background of different groups within these countries. Accordingly, being secular and having a Western-style education and life style are favored in the public institutions of both countries, including hospitals. For instance, Meira Weiss (2001) discusses how the Israeli medical professionals and Zionist state, like colonial missionaries, viewed the Yemenite immigrants as primitives to be “cleaned and civilized.” Weiss relates this view to the disappearance of about 4000 Yemenite babies from hospitals and schools in the transit camps for new immigrants in the 1950s. Many of these babies were often sterilized and given for adoption to Ashkenazi families in Israel and in Europe, and according to one rumor, to Holocaust survivors, in order to assimilate Middle Eastern Jews into the dominant Ashkenazi group to maintain collective and national identity. Their full names are never recorded by the Israeli institutions in order to keep these babies anonymous and to prevent the parents from tracking down the adoptions. Although the parents of these babies are told that these babies died in the hospitals and were given formal papers, the parents did not believe this, since they weren’t allowed to see the body of their dead babies.

This issue is still vivid today because the parents are still angry at the state and medical professionals and try to find their children, and also because the new generation of Yemenite children who know that they are adopted look for their biological families. Weiss argues that a collective identity revolves around “the chosen body” and “since the early days of nation-building has been regulated to form a new person.” Weiss notes

that the Ashkenazi are still dominant in the medical profession and state institutions, which makes it harder for Yemeni Jews to find their family members even now. Similarly, Karen Pliskin (1987) writes about the problems that the Iranian Jews experience in their interactions with the medical staff in Israel. The book gives examples from the perspective of Iranian Jewish patients and focuses on how the medical staff disdains or overlooks the popular views of illness and health in this group, which are informed by their cultural and communal background as well as their own interpretation of Judaism. The medical staff also tries to teach and impose the biomedical explanations of diseases in order to make sure that the treatment they prescribed will be followed by patients who mostly feel uncomfortable in the hospital. The patients often become aware of the suspicion and disapproval of health care providers and thus feel alienated in the hospital setting.

In Turkey, several doctors who wrote about their professional experience categorize the health “beliefs” and practices of patients from rural backgrounds and various ethnic origins, such as the Kurdish one, as traditional, and believe that they will become obsolete when Turkish modernization is fully realized. Those doctors often define “traditional” health practices as odd, ridiculous or irrational, depending on their degree of tolerance and empathy (Minkari 1993; Martı, 1996, 2004; Özen, 2003). Those attitudes coincide with a general reaction among many health care providers against the complementary and alternative methods<sup>21</sup>. Altay Martı (1996, 2004), who is a doctor with leftists views and who grew up in Diyarbakır in the Southeast of Turkey, where he

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<sup>21</sup> Due to their professional association with and allegiance to modernity many health care providers and scientists are either skeptical or reactionary against alternative or complementary medical methods. Several doctors, whom I talked during my fieldwork, noted that they cannot accept those methods to be called “alternative” as they can never be considered as such, or compared to the modern medicine in any way. I will discuss that issue in detail and I will cover the patients’ perspective on complementary and alternative medical systems in Chapter 5.

also practiced his profession for several years, sympathizes with non-biomedical views and practices more than most of the other Turkish doctors. He views the folk healers as “wizards with experience” who heal their patients through setting their bones, massages and prayers, which are informed more by ancient Central Asian Turkic and shamanistic traditions rather than the Islamic tradition. He also notes that those healing methods are a necessity for a large number of people who cannot afford health care and who have no access to it, since many people cannot get insurance because they work as farmers in rural places or in the informal sector.

Nevertheless, he also points to a few examples where he considered his patients’ explanations of their disease to be ridiculous, as in the example of an old man who said that his headache is caused by a stork attacked him and left a mark on his forehead sixty years ago. Martı also talks about “bizarre health problems” which are known locally among the Kurdish neighborhoods of Diyarbakır, which are treated by wise women who know the prayers and how to massage, such as “the fall of *poçik*” (*poçik düşmesi*). This is a cultural construction of a muscle problem, which is common among active children who play in the streets all day long and which gives them pain when they try to sit down. The injuries related to *poçik* (the muscle which is thought to be at the bottom end of spine) are common in the Eastern and Central Anatolia, and several doctors I talked to believe that these injuries were invented by the parents in order to keep their over active children in control.

Unlike Martı, many doctors, from previous generations and with a more elitist socio-economic background, such as Özen (2003) are less sympathetic towards the people who adopt alternative medical methods and explanations out of “ignorance and despair.” They reflect a common belief among the health care providers and scientists

that these “ignorant and desperate” people are used and abused by “charlatans” who claim to know Islamic and folk healing methods (Dole, 2004). Some Turkish doctors, such as Hikmet Uluğ (1997), agree with the reports of the WHO, which state that the complementary and alternative medical systems are essential in the treatment and eradication of prevalent diseases, such as cancer, which the biomedical institutions have problems with finding a cure. However, for Uluğ a proper classification of complementary and alternative medical methods that have a scientific basis, such as aromatherapy and massage therapy, and exclusion of “charlatans” are the prerequisites for such integration. Although Uluğ represents a general skepticism among health care providers about complementary and alternative medical systems, there are also a few doctors opposed to the dominant modernist perspective in the Turkish medical realm. Those doctors, who are mostly from the younger generations, have expressed views which favor an “Islamic medicine” more informed by the Turkish folk medical views and practices since the 1990s. For instance, according to “Beyond Modern Medicine” (Serdar et al., 1994), which is written by a group of doctors who advocate for the re-institutionalization of Islamic medicine in Turkey, modern medicine has collapsed in general because human beings could not manage to solve their spiritual and psychological dilemmas through modern medical discourses and practices. Despite the variety in these arguments about the complementary or alternative medical systems, very few of them benefit from the social science literature on health and illness. Similarly, Turkish social scientists rarely take account of the Turkish doctors’ narratives, since until recently they have mostly focused on macro-level analysis and quantitative research methods. However, the arguments of Turkish doctors about the cancer patients and “traditional healing methods” have helped me to provide a critical reading of

Turkish modernity and its historical transformation as they are reflected in Turkish health care<sup>22</sup>. Those arguments also reveal a disdain that I located in İstanbul against the “ignorant” patients who migrated from the “East” or “Anatolia” (terms that imply they may be Kurdish or coming from a rural place), similar to the attitude of Ashkenazi doctors against the Sephardic patients.

The recent works I have cited here show that the combination of political-economy and interpretive-discursive approaches are needed in order to analyze how biomedicine is internalized in a particular social context and how it interacts with other cultural conceptions and practices of health and illness. Thanks to the combination of those approaches, we are able to investigate fully the perspectives of patients and health care providers and the interactions between these two groups, as well as the larger social, political and economic dynamics which influence those perspectives and interactions. Having a cultural-interpretive approach and narrative analysis are especially crucial for understanding the cancer patients’ illness experiences in Turkey, since many of those patients are unable to express their views on their health and illness in the medical contexts. Those patients’ illness narratives, which often include the problems they encountered in medical settings and in society, are rarely examined by social sciences in Turkey, and they are mostly downplayed by the policy makers who work for the improvement of health system. However, a thorough analysis of those narratives will indicate the problems of biomedicine in Turkey, in terms of its institutionalization process and interactions with other health conceptions and practices, as well as the problems of Turkish modernity concerning the inclusion of all the Turkish citizens on an

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<sup>22</sup> In order to learn about the doctors’ views on cancer, cancer patients, and non-biomedical healing methods, I collected the books and articles, which are written by doctors on those topics. I also interviewed 15 doctors and 7 nurses at Güvercin and SSK on the same topics.

equal basis. I aim at such an analysis, and in the next chapter I will describe the medical and social conceptions of cancer in Turkey before focusing on the Turkish cancer patients' illness narratives.

## Chapter 3

### **The Social and Medical Conceptions of Cancer and Other Major Diseases in Turkey**

On a snowy day in İstanbul, I was on my way to SSK hospital to have interviews with the cancer patients there, and the taxi, which I took in my neighborhood, could barely move in the notorious İstanbul traffic, which got even worse because of the snow. During a particularly long wait in the traffic jam, the taxi driver told me that he is familiar with me, since I have often taken taxis from their car service in the last few months, and he added, “I also notice that you keep going to hospitals. I hope there is nothing wrong with your health.” When I explained that I am doing a research on cancer patients in those hospitals, he said: “You know, I am so pissed off at the United States, instead of bombing all over Afghanistan and Iraq, they could have used that money to produce all those weapons for research on cancer, and that illness would be totally eradicated from the world immediately. So, we are all suffering because of cancer in vain in the age of rapid scientific and technological improvements.” When he asked me what I thought about this argument, I told him that perhaps he was right.

I heard the same argument over and over again from people with different occupations and socio-economic backgrounds during my fieldwork. Interestingly, the same connection between cancer and war was also made by the French Prime Minister General Charles de Gaulle in an international congress on cancer in 1957, when he said in his opening speech: “Let’s stop having wars, let’s abolish our armies and allocate our national defense budget to the struggle against cancer” (TKASK, 1999). These examples

reminded me of the military or war metaphors that are often used in describing cancer and AIDS in different societies. The war metaphors, which often see the body as a castle and microbes as the enemies to be conquered, are often used in the biomedical and popular discourses for various major illnesses since the early 20<sup>th</sup> century. (Sontag, 1978, 1989; Martin, 1994). Emily Martin (1994) indicates that those metaphors became especially common in the 1980s onwards, with the explanation of illnesses through the human immune system and how it works against the “enemies,” which are both in the outside and inside of the body. The recent armed conflicts, which have a global impact, such as the US occupation of Iraq, also make it easier to relate the medical war against illnesses to the actual wars in one way or another, since both wars induce fear and anxiety. Cancer’s rapid, and often undetected, development in the patient’s body and its harsh treatment, which has major side-effects for the patients, also make the use of war metaphors in describing that illness more popular. Recent social and political dynamics and debates also inform the cancer patients’ experiences and narratives and provide new meanings for the use of war metaphors about cancer. The more the collaboration between the political and medical authorities in fighting against cancer is dissolved, the more the “war against cancer” takes place at an individual level, both in terms of having a healthy life in order to avoid cancer, and doing one’s best for an effective medical treatment. Eleven patients I interviewed emphasized that they fight against cancer “by themselves,” and that only few people, whom they feel close to, are “somewhat involved” in that fight.

Since the 1980s, medical and political authorities, scholars and journalists have often related the “war against cancer” to contemporary social issues, such as rapid urbanization and industrialization, migration and environmental problems. Cancer patients evaluate those issues in accord with their own socio-economic background and

illness experiences, which often include an expensive, long-term treatment process and regular interaction with health care providers. They try to relate those larger, public issues to the drastic changes in their lives, bodies and social interactions, the meaning of their lives, and their relationships with other people. However, those individual efforts of coping with the social, psychological and physiological damages of cancer are rarely reflected in the public debates and policies on cancer. The fact that the patients' individual voices are largely missing in the public debates and policies on cancer has historical roots, since the authoritarian and hierarchical aspects of modern medicine in Turkey in the late 19<sup>th</sup> century informed the medical and social conceptions of health and illness issues.

Cancer has been the most commonly discussed disease in Turkish society since the 1980s, and particular themes and cultural codes shape these discussions to a large extent. Those themes and cultural codes play an important role in defining cancer as a social issue, which affect everyone in the society, especially the cancer patients, their relatives and people who consider themselves as being at risk of having cancer. Those themes and codes are embedded in individual illness narratives to the extent that they make it difficult for the cancer patients to find their own voice and reflect their own perspective in talking about their struggles as individuals. Therefore, there is a gap between the cancer patients' illness narratives and social or medical conceptions of cancer, which leads to the further marginalization of the patients in the society and medical realm.

In this chapter, I will investigate the social and medical conceptions of cancer and relate them to the conceptions of other major diseases in Turkey from the late 19<sup>th</sup> century to 2000s. I will indicate the similarities between the social and medical conceptions of cancer and those of other major illnesses, especially in terms of collaborations and

conflicts among the political and medical authorities and ambivalence against the internalization of Western medical practices and life styles. Although, there are few historical studies on those issues, the topic is an important one in order to understand the debates around cancer today, since the patterns of medical, social and political “war against diseases” show similarities throughout the history.

**Conceptions of Illnesses during the Fall of Ottoman Empire:** The fall of Ottoman Empire and foundation of the Turkish Republic took place during several decades of consecutive uprisings and wars between 1878-1923. The newly modernized Turkish army fought battles in North Africa, Middle East, Russia and the Balkans, most of which they lost. The army’s travels back and forth to İstanbul and to the remote corners of the Empire for those wars facilitated the spread of infectious diseases, such as cholera, typhoid, typhus, tuberculosis, syphilis and influenza, both in the rural areas where the army stopped for few days and in İstanbul where the army resided (Dağlar, 2004). The political and medical authorities were aware of the fact that the army played a major role in transmission of epidemics and that there was a considerable difference between them and European soldiers in terms of access to health care both in wartime and in peace. Those concerns led them to prioritize the health of the members of military when they introduced modern, Western institutions and practices, and as noted earlier the first Western-style medical school, which was opened in İstanbul in 1827, was also a military one.

The Ottoman civil population was also prone to epidemics, especially in the rural areas, because of increasing poverty and malnourishment, which were caused by the general impoverishment of the country. The loss of agricultural lands as a result of the

wars put an extra burden on the peasants of Anatolia and Thrace to produce food to feed the population in the cities, and the economic crises led the last Ottoman sultans to cut back investment in rural areas. The sultans gave preference to the major cities because of their ambitions to create cities similar to European ones, with their sewage systems, wide streets, parks, cultural centers, and European-style palaces<sup>23</sup>, and they spent considerable amounts of money, most of which was borrowed from European countries. Ottoman intellectuals harshly criticized those investments, which increased the social and economic disparities between the rural and urban areas and played an important role in the bankruptcy of the empire (Hourani, 1992; Çelik, 1996).

The health and living conditions were worse in the small cities and rural areas, and the introduction of modern, Western medical institutions in the Ottoman Empire increased the gap between those places and large Ottoman cities in terms of health standards and access to health care. The first European-style hospitals and medical schools were founded in the densely populated, cosmopolitan cities of the Empire, such as İstanbul and İzmir, and prioritized the elite population in those cities. That policy affected the geographical distribution of health care services throughout the country, which became similar to the countries that were colonized by Europeans, such as Egypt and Tunis, although the Ottoman Empire was not colonized in political terms. (Moulin, 1996; Watts, 1997). The Turkish Republic inherited those problems and inequalities, which still persist today to a large extent and affect the health policies and conceptions of

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<sup>23</sup> The Topkapı palace, which is the traditional Ottoman palace, consists of several small buildings situated in a large garden that is surrounded by walls and gates. In the 19<sup>th</sup> century, however, in accord with the adoption of European architectural styles, a series of new palaces, such as Yıldız and Dolmabahçe, which mainly consist of one colossal building, were built.

illnesses, despite the application of several health reforms and improvement projects in the 20<sup>th</sup> century.

In the last half of the 19<sup>th</sup> century, the unequal living conditions increased the migration from the rural areas to the large cities. These waves of migration were also combined with the mass migrations from the lands that were lost in wars in the Balkans, Russia and the Middle East, and the migrants intermingled with the old inhabitants of the cities. The new social spaces of the city, such as European-style cafes and restaurants, large-scale schools, work places and factories facilitated the intermingling of people with different socio-economic backgrounds. The epidemics of the late 19<sup>th</sup> century thus became a common fear, independent of their socio-economic status and demographic characteristics (Çelik, 1996, Dağlar, 2004). Although, the epidemics threatened the whole population, the urban elite had a better chance for survival, since they had better living conditions and a better access to the recently opened modern hospitals, which had the most recent medical knowledge and technology.

Although they favored the army and urban elite, the measures adopted to quell the epidemic, such as large-scale vaccination campaigns and quarantine, also affected the whole Ottoman population and their conceptions of illnesses (Moulin, 1996). The Ottoman rulers were convinced that Western medicine was more effective in fighting epidemics, and shaped the health policy in accord with that conviction. Ottoman doctors were sent to European countries and European specialists were invited to the Ottoman Empire, in order to establish Western-style institutions and educate health scientists and care providers. However, as I discussed in Chapter 1, the Ottoman medical students who were trained in the Western-style medical schools and in Europe, also adopted the social and political views which were popular in Europe at that time, such as freedom of thought

and expression, and that led them to challenge the Sultans' authority. Those students' views on the democratization and the social and political modernization of the country were also often in conflict with the Sultans' policies. This created problems between the political elites and medical authorities, and the Sultans often sent their spies to the hospitals and medical schools.

**The Institutional War against Diseases in the Turkish Republic:** Health problems were an important priority in the earlier decades of the Turkish Republic, which was founded in 1923. The ministry of health was one of the earliest ministries of the first government, and the first comprehensive health plan designed in 1926, was implemented throughout the whole country. The primary aim of that plan was to eradicate the major epidemics and other health problems that were caused by the consecutive wars, such as malnutrition, both in the rural and urban areas. That aim was supported by a new and strong sense of nationalism, which included the project to create a healthy, fit and young nation and heal the wounds of wars, which had led to the fall of the Ottoman Empire. The founder of the Republic, Mustafa Kemal Atatürk, influenced by the views of Jean-Jacques Rousseau, adopted the motto: "a healthy mind exists in a healthy body," and this helped the earlier generations of medical and political authorities to develop a holistic approach on health issues.

Atatürk also sent the Turkish medical experts to various European countries, so that they adopt those countries' models on how to improve the physical and health condition of their people. (SB, 1973; TCTA, 1985). In addition to the hospitals and medical schools, where the modern Western medicine was applied, the schools and public

houses adopted modernized folk dances<sup>24</sup> and Swedish gymnastics, in accord with the suggestions of the medical experts who had conducted research in Europe (Öztürkmen, 1998). However, the problem of adopting the “good” side of Western culture, while leaving its “bad” side, presented a challenge for the intellectuals and politicians who also wanted to combine the Western and Turkish national characteristics. The conflicting views towards the West were also reflected in debates about how to adopt the European health practices in order to raise new and healthy Turkish generations. The West was commonly seen as the bedrock of modern science, which Atatürk described as the “torch” guiding future generations to a successful life in a material and spiritual sense. However, the problem of the “degraded life styles” of the West became an issue for some Turkish intellectuals and politicians. For example, several novelists, such as Yakup Kadri Karaosmanoğlu, Peyami Safa and Aka Gündüz, who played an important role in shaping the nationalist discourse, criticized that the “new habits” of excessive drinking, smoking, promiscuity, and conspicuous consumption that came with the excessive Turkish imitation of the West. In their view, the purity of the village life, which represents the essence of Turkishness, was contrasted with life in İstanbul, which was seen as having been corrupted since the last decades of the Ottoman Empire. The view of the degraded and corrupted life styles in the West, as opposed to the pure Turkish essence, found in the villages, still influences the social conception of health and illness issues today, as I will describe later in this chapter and in Chapter 5.

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<sup>24</sup> Turkish nationalism is very much influenced by the German nationalism, in the sense of thinking that the village life reflects the pure essence of Turkishness. In order to represent this essence in a “universal” way, musicians had an extensive research in the villages and collected different patterns of costumes, music and dances in order to “modernize,” standardize and spread them throughout the whole country (Öztürkmen, 1998).

The focus on health issues in the rural areas during the foundational years of Turkey arose not only from the view that glorified the “village” as the essence of Turkishness but also from the efforts to reverse the Ottoman health policies which had given priority to the health issues in the cities. Another major difference between the health policies of the Ottoman Empire and the Turkish republic is that during the earlier decades of the republic, the politicians provided full support for the health scientists and health care providers in their task of improving the society in medical and social terms. This political support increased the professional prestige and social status of health scientists and health care providers. It also underlined their pivotal role in fighting diseases in close collaborations with the political authorities.

One of the first tasks of the Ministry of health was to create departments of “War against Malaria” and “War against Tuberculosis” (SB, 1973), since both of those diseases had badly affected the health of the population, both in rural and urban areas. The Ministry initiated rapid infrastructural improvements, opened hospitals and clinics throughout the country, and obliged the newly graduated medical students to work in the villages and to improve living conditions. The department of “War against Malaria” also worked remarkably well between 1930-1970, draining the marshlands in Southern Turkey in order to eradicate the mosquitoes that caused malaria. The “War against Tuberculosis” department also established clinics in the main districts of every major city and town in order to detect and treat this disease. Although TB still exists in Turkey today, it is kept under control to a large extent, because of the requirement that the chest of every student and state employee is regularly x-rayed. There is, however, a new threat of multi drug resistant tuberculosis, which affects the poorest people, who often work in informal sector

in the cities and who have limited access to the health care services, since they do not have any insurance (Yasin, 2007).

Despite the successes of the first health reforms in improving the health conditions in rural areas and in eradicating the major epidemics that had affected the population since the 19<sup>th</sup> century, those reforms slowed down considerably in the 1940s. This is related to the economic difficulties caused by the Second World War, a decrease in the early nationalist enthusiasm for creating a healthier population, and also to the death of Atatürk, who had initiated the reforms (SB, 1973). However, what now remains from the 19<sup>th</sup> century of wars, epidemics, and the early 20<sup>th</sup> century health plans is the fear of infection, the association between disease with the degraded ways of Western living, and the view that the state and health professionals should organize a “war” against the major diseases and improve health and living conditions. Those views of health and illness also influence the social conception of cancer in Turkey in various ways, which I will describe in the following sections of this chapter.

**The Medical Institutions for “War against Cancer”:** Although there were several doctors who specialized in treating cancer in Turkey as early as the 1920s, first cancer institution, the “Turkish Association for Cancer Research and Control”<sup>25</sup> was founded in 1947 in Ankara. One of the founders was an internationally acclaimed woman doctor, Perihan Çambel, who stated that the aims of the institution as “enlightening the nation on cancer, detecting people with cancer and handling their treatment through better organized and equipped institutions.” She also defined their principal mission were

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<sup>25</sup> The direct translation of the Turkish name of the institution to English is the “Turkish Association for Cancer Research and War against Cancer.” However, the word “war” has become “control” in the translation of the association’s name into English.

“leading the case of cancer through organized, rational and scientific ways and protecting this case from unscientific and unorganized treatments.” The association received private donations from its members, as well as state funds for the construction of its main building and library (TKASK, 1999). Those words reflect the medical self-confidence in terms of dealing with the “case of cancer,” and excluded other unscientific treatments. The war against cancer was to be “scientific, rational and organized,” and it would have the support of state and society.

Another well-known founder of the institution, İrfan Titiz, explained that the doctors preferred not to use the word cancer while talking to the cancer patients because they respected the patients’ dignity and pride. According to Titiz, the doctors should set an example with their moral strength and belief in modern medicine, by avoiding the word cancer and using instead such indirect expressions as “neoplasm.” Titiz also emphasized that doctors should not create a sense of panic and fear while treating the disease, and that they should avoid giving the impression that it was a problem without a solution. Titiz noted that cancer is a social disease and that educating people about cancer would make a big difference. He warned his readers against the charlatans who claimed that they could cure cancer with words (meaning prayers), roots and herbs, and indicated that cancer could be cured only by a careful doctor’s medical treatment (TKASK, 1999). During my fieldwork, I noticed that Titiz’s suggestion of not using the word cancer in talking to the patients is still largely followed by the Turkish health care providers, and instead, “tumor” or “hard entity” (*kitle*) is preferred. The doctors and nurses now say that avoidance of the word cancer, which I will discuss in detail in Chapter 4 and 8, in contrast to Titiz’s statements, has more to do with the patient’s morale, rather than dignity. However, the ideological reaction of today’s health care providers against the unscientific

“charlatans” is as strong as in the earlier decades of the republic, as I will discuss later on this chapter and in Chapter 5.

From the 1960s onwards, cancer has replaced the previous epidemics in Turkey, in terms of inducing anxiety and fear. Earlier epidemics have been either eradicated or kept under control at that time, as cancer has become more visible, with slow but regular increases in cancer rates. The “war” against cancer” also became more pronounced, and the number of cancer hospitals increased rapidly in the 1960s and 1970s. The social and medical services of the “Turkish Association for Cancer Research and Control” have also spread to the major cities of Turkey. The institution became known for its charity activities, the distribution of brochures to hospitals and schools, and for the annual cancer-theme painting competitions in primary and high schools, which target both rural and urban populations. Since the 1970s, the institution has organized fashion shows, concerts, plays and other artistic activities with well-known artists, who participated on a voluntary basis, and raised money in order to build new cancer clinics or to renovate the existing ones.

Since the 1960s, the ministry of health has also increased its activities for the eradication of cancer. In 1962, a separate section, the “Section of War against Cancer” was founded in the Turkish Ministry of Health. This became the third section built to fight against a particular disease after the sections on malaria and tuberculosis (SB, 2005). The section aimed at supervising all the medical institutions that were responsible for the treatment of cancer, and organizing educational programs for the health care providers. It also informed the Turkish population about how to protect themselves from cancer and how to cater to the specific needs of cancer patients. In 1970, the section declared the week of 1-7 April to be “Cancer Week,” organized press conferences, educational

seminars and talks, and published posters and stamps so that people could become more “conscious” about the disease.

In the 1980s cancer gained more visibility and became the most discussed and feared illness in the society, and the increase in the activities of the cancer associations reflect that fact. In 1982, cancer became a reportable disease, for clinics and laboratories inform to the Ministry of Health. The reports were to provide the number of cancer patients who visited their institutions and the type of their cancer, without revealing the name of the patients. The institutions should also prepare weekly, monthly and yearly reports and present these to the Ministry. However, except for the large-scale state hospitals, many institutions failed to present these reports accurately, possibly because there are no sanctions for not doing so. In 1983, the Ministry of Health considerably increased the scale and budget of the “Section of War against Cancer,” so that it could better oversee cancer education, and cancer treatment (SB, 2005). The “Turkish Association for Cancer Research and Control” also began to hold “patient’s morale days” where the doctors visit cancer wards, together with celebrities, football players or politicians, who chat with the patients and give interviews to the journalists who follow the events. (TKASK, 1999). Several other cancer organizations were also founded and followed the example of the “Turkish Association for Cancer Research and Control” in raising consciousness for cancer through raising money with the help of celebrities and public figures, who work closely with the medical authorities and health care providers. When the media covered the news about the activities of such organizations, the voice of cancer patients was much less heard than the statements of the “kind and generous” public figures and medical authorities, who dominated those events.

The increase in the institutional activities for the “war against cancer,” at the expense of war against other diseases, also has to do with the health reforms in Turkey. Health conditions throughout the country improved considerably, thanks to the socialization of health laws in the 1960s, which were aimed at providing better access to the hospitals, especially in the rural areas. Small-scale clinics in the remote corners of cities and rural areas became equipped with doctors, nurses and midwives who knew about the health problems of the regions in which they worked (SB, 1973). Those laws aimed at reducing the effect of the socio-economic inequalities in health care, and aimed at creating a healthier population, as in the health projects of the 1920s and 1930s. These health projects stopped in the 1970s because of the military takeover and the change of government, resulting in limited extensions of health care. However, the laws have led to the persistence of the popular view that state could fight effectively against the infectious diseases. Accordingly, many people still believe that the state also has the power to solve the other health and health care access problems, if only it did not face political and economic conflicts such as high inflation, military takeover and civil war in the Southeast. This view also results from the common belief, reminiscent of the nation building years of 1920s and 1930s, that there should be a close collaboration between the state and health care providers and health scientists.

Despite the privatization in medicine and the new health reform, which prioritizes the local rulers at the expense of state control, the state is still highly visible in medical action. Moreover, my research indicates that the private medical institutions are still seen as a “luxury” for a majority of cancer patients, who visit them only if they personally know a good doctor there, or to consult doctors to confirm their ongoing treatment in a public hospital. The belief that political authorities can solve the issues of health and

illness also depends on the results of the new health reform, since the people with state insurance will then access to private hospitals.

**Social and Medical Conceptions of Cancer in the 1970s and 1980s:** As noted above, both the number of cancer patients and mortality rates from cancer continued to increase slowly but regularly in the 1980s, and relatedly, the media began to cover news on cancer more often. The news mostly included general information about the causes and treatment of cancer translated from the American and European media. Partly as a result of the historical fear of infectious diseases and lack of information on cancer, many people in Turkey considered cancer to be an infectious disease as well. The health care providers I talked to said that many people stopped having any contact with cancer patients they knew in the 1980s. Although explaining that cancer is not a contagious disease is one of the main aims of cancer organizations and health care providers<sup>26</sup>, this view still persists today to some extent, especially among the people who did not attend primary or high school where students learn about cancer in the “cancer week” every year.

Lerna, an Armenian breast cancer patient in her sixties explained to me that she grew up in a rural place in Sivas and went to an Armenian primary school there for only three years. She was really surprised when the doctor told her that her cancer was not infectious. Lerna added: “Since I have such a hard time to believe that, I can’t really blame my friends and family members who avoid seeing me, thinking that they may also get infected with cancer. It is even a miracle that my husband believed in me and the

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<sup>26</sup> Although few forms of cancer is infectious, the doctors I have talked to, stressed that they do not want to tell this to their patients unless their cancer is due to an infection, since they believe that the crucial moral support, which the patients have from their loved ones are crucial for their treatment, may decrease considerably in that case.

doctor, and that he is still together with me.” She told me that she tried hard to convince the people around her that they won’t get cancer if they get close to her, but she said that only her husband and one of her neighbors believed her and stuck with her. She came to İstanbul after she married in her late teens and has never had a job in the city. Since her husband is a night guard in a factory, his salary can barely support her cancer treatment. Lerna said she badly need economic and social support from the people around her or from charity organizations, but she does not know whom to turn to, because everyone avoids her. Similar complaints came from three other cancer patients who also had a disadvantaged socio-economic background and needed social and economic support.

Several doctors at SSK noted that many of their patients think that a major illness is by definition an infectious one, since they grew up in the times when diseases, such as tuberculosis and malaria, induced fear. The Turkish word for infectious (*bulaşıcı*) is also used outside of medical context, especially when people refer to something, previously clean, becomes dirty or soiled, such as mud on one’s new shoes, and someone who acquired bad habits from another person, such as gambling and smoking. The word is often used in a negative way and combined with the word epidemic (*salgın*), also when people refer to a popular trend or habit, as in the recent example of the “nationalism epidemic” which is discussed by several journalists. Turkish does not have a word for pandemic, but several patients I interviewed argued that cancer became an epidemic in certain regions of Turkey, such as Thrace and Black Sea coast, in order to refer to the high rates of cancer in these regions.

Besides the fear of infection, cancer was associated with a particular group of people in the 1970s and 1980s. The common belief was that urban, professional, upper-middle class people who, at least in their sixties, were more likely to have cancer, since

they led more stressful lives and they smoked more. In the slogans of the Turkish Association for Cancer Research and Control, smoking, drinking alcohol, and having a stressful life in the city were contrasted with a “clean” life that is close to nature, which would prevent cancer. The slogans, which became more common after the 1970s emphasized regular check-up visits to the doctor for early detection, especially for the people who were associated with the risk of having cancer. The most prevalent and long lasting of these slogans were the ones against smoking and consuming alcohol, and “Don’t be afraid of cancer, be afraid of being late for the detection of cancer” and “Early detection saves lives” (TKASK, 1999). The slogans emphasize the medicalization of everyday life, by claiming that surviving cancer is only a matter of visiting the hospital on time, and blaming the individual’s “unhealthy behaviors” for their cancer. They also play a pivotal role in shaping this social conception of cancer since the 1970s, because Turkish people have been often exposed to them in their everyday lives through their schools, billboards, sheet banners on the streets and the media.

The cancer associations have also tried to challenge the common association between cancer and death through their slogans, which emphasize that cancer is curable through medical treatment. However, the fact that cancer is often indirectly referred to as a “lethal” or “grave” disease in the obituaries and daily conversations also reinforced the association between death and cancer despite the slogans. The failures in medical treatment and detection also strengthened this association, and have increased the cancer patients’ efforts to find cures in alternative or complementary healing methods. This is the case despite the efforts of the health care providers, who have held large-scale campaigns against the “charlatans.” They say such people try to gain from the despair of cancer patients, pretending they could cure cancer “with prayers, roots and herbs.” For

instance, one of the slogans created by the Turkish Association for Cancer Research and Control, and used between 1930-1990, states: “Don’t ever go to charlatans, only the doctors can guide you” (TKASK, 1999).

### **The Rift between the Political and Medical Authorities and the Case of Özel:**

The medical fight against the “charlatans” gained a new political dimensions in 1986, when Ziya Özel, a surgeon interested in “heterodox medical knowledge,” claimed that he could cure cancer patients with a drug which he made by using oleander leaves (Gürsoy, 1996). When Turgut Özal, the Prime Minister at the time, agreed to support him financially for the commercialization of the drug, both Özal and Özel immediately became the target of health scientist and health care providers (Tempo, 2003; Hürriyet, 2003). The debates on this issue were covered in media for several months, and took the form of a campaign against the “charlatan-doctor.” The criticisms against Özel included charges that he was trying to fool the whole society and that his findings were not based on proper scientific research. As a result of these criticisms, doctors and medical scientists questioned Özel’s academic and professional career, and rapidly marginalized him in their professional community (Gürsoy, 1996, Tempo, 2003). The campaign also targeted the Prime Minister Özal, since he was blamed for trying to divert the attention of the public from the economic and political problems by promoting the “story” of a Turkish doctor who had found a cure for cancer. As a result of this campaign against him, Ziya Özel moved to the United States in 1988, and founded a laboratory in Texas where he could conduct his oleander research. In 1992, he received the patent for his new oleander drug, “Anvirzel,” which is now available in the United States, Honduras and Ireland (Hürriyet, 2003). Although Özel rarely gave interviews to the Turkish media after

moving to the US, he still continues his research and production of cancer drugs and the effect of oleander in curing cancer is still debated among medical researchers (Gürsoy, 1996).

In order to understand the reactions against Özal and Özel by the health care providers and health scientists, we have to analyze the larger political and social framework of the 1980s, where an important rift took place between the political and medical authorities, because of the military takeover in the 1980. The military regime of 1980-1983 maintained severe limitations on human rights and applied extensive censorship in the media and everyday life. Torture of people in custody and prisoners, especially those charged for political reasons, became common. Several doctors revealed that their autopsy reports conducted for people who died in prisons or police stations confirmed torture. They also cooperated with the national and international media in covering the news on torture in Turkey. As a result, the military regime blame the doctors as being “unpatriotic,” and a rift arose between the politicians and medical authorities because of the incident (Martı, 1995).

The Prime Minister, Turgut Özal came to power through elections and tried to reverse the policies of the military regime by promoting economic and political liberalism, privatization and consumerism. He has initiated a rapid and often unregulated urbanization and industrialization process, often neglecting the health and living conditions of the poor and environmental standards. Özal started the “five star hospitals” age, by promoting the privatization in medicine, and as I described in Chapter 1, that drew strong reactions from the health care providers and health scientists, who refuse to have patron-client relations in the hospitals. Those criticisms were also often combined with the ones that claim that Özal’s policies downplay the importance environmental

health, and the health and living conditions of poor people (Soyer, 2004). These criticisms led to the increase in the rift between the political and medical authorities, which also affected the debates on Ziya Özel and his new drug, as well as the debates on Chernobyl's effect on Turkey. In fact, the rather unitary voice of the medical and political authorities who fully collaborated in their fight against illnesses in the earlier decades of the Turkish republic, have gradually turned to myriad of voices since the 1980s, because of the major disagreements about why cancer rates have increased and how to prevent it. The disagreements are not only between the politicians and medical authorities, but also within those parties, and they have caused mistrust among the “lay people” towards those authorities.

**The Chernobyl Accident and its Effects on Cancer Rates in Turkey:** The political and medical authorities had another major disagreement about the Chernobyl accident in Russia, which also took place in 1986. The politicians, health scientists, health care providers, journalists and activists took sides in the debate about how the Chernobyl accident affected Turkey, and that debate had a political component, similar to the campaign against Ziya Özel. Turkey first received radioactive clouds from Chernobyl on the borders with Bulgaria and Greece, a week after the accident in April 1986, and then in its eastern Black Sea coast after the second Chernobyl explosions in May (Chernobyl. Info). Both sets of clouds brought heavy rain to those regions, and the Turkish army and Turkish Atomic Energy Institution (TAEK) detected a high radioactive level on the air. Ahmet Yüksel Özemre, the head of TAEK, told the media that there was nothing to be scared of, since “they took all the precautions.” TAEK warned people in Thrace about the first clouds and the measures to be taken, such as not going outside and

not to harvest during or right after the showers, but both TAEK and Turkish Army hid information about the second set of clouds in the eastern Black Sea coast, which were more dangerous. The clouds remained stuck between the sea and high mountains and had a more intensive effect on the Black Sea region (Soner, 2005). The contaminated areas in Turkey include big cities such as Trabzon, Rize, Ordu, Samsun, and Edirne, as well as intensive agricultural lands on the Black Sea coast where crops providing major economic revenues are raised, such as tea and hazelnut.

Following the accident, the effects of Chernobyl in Turkey were discussed concerning large quantities of contaminated tea and hazelnut, the major export crops from Turkey to Europe, and what to do with them. Countries in the European Union were alarmed about the effects of Chernobyl and regularly tested every imported product. Hazelnut and tea from Turkey were found to have radiation levels much higher than the standards set by the EU. As a result, European countries stopped importing these products from Turkey for three years, and, led by England and Germany, those countries issued international warning reports. The Turkish media published these reports together with the news of the ban, creating a big panic in the fall of 1986. The contaminated plants, when combined with the high radioactivity in the air and water were said to constitute a potential danger for cancer, especially for the people living in the Thrace and Black Sea regions, but also for all the Turkish people who consumed the contaminated products (Soner, 2005; lazuri.com)

In order to quell this panic, the Prime Minister, Turgut Özal and Minister of Commerce and Industry, Cahit Aral, claimed that “even if contaminated, the radiation level in both of these products are so low that they are harmless for people’s health.” They also started a mass campaign in order to prove that drinking the tea, which is the

most common drink in Turkey, was harmless. Both ministers made a show of drinking tea in press conferences and on TV shows, explaining that the argument about tea being contaminated is a British conspiracy against the Turkish tea, because the British tea cannot compete with the Turkish tea in terms of taste and quality. In one of his speeches, Turgut Özal went as far as claiming that radioactive tea is tastier. Özal, Özdemir and Aral tried to downplay the panic with casual, joking remarks such as “a little bit of radiation is good for the health” and “a little bit of radiation increases sexual power” (NKP, 2005; Soner, 2005). However, the strategy of downplaying the Chernobyl effect backfired and the panic about the “Chernobyl effect” has increased over the years. Many people blamed those politicians for being irresponsible and for not caring about the people’s health and for prioritizing economic interests instead (Dündar, 2005).

Several journalists also blamed the politicians, and the acclaimed journalist, Şükran Soner (2005), claimed that Özal had said: “There is nothing to be done. 3000 to 5000 people would die of cancer and this case would be closed. If we deal with this problem too much, our economy would be totally destroyed.” The media also reported that Özal had banned the scientists in the universities from researching and publishing the radiation levels in tea and other possibly contaminated products and exploring the Chernobyl’s potential hazards on Turkish people’s health, in order to avoid panic. Several scientists criticized that ban, and claimed that it is crucial to conduct research on the “Chernobyl effect,” which would show itself in Turkish cancer statistics in 10-15 years. (NKP, 2005, Soner, 2005). In return, Özal and Özdemir blamed the media and the scholars who had alerted people about the radiation levels in tea and hazelnut calling them leftists who were not being patriotic and prioritizing national interests.

Finally in 1987, as a result of the criticisms, the government decided to stop marketing tea from 1986 harvests, and destroyed 145.000 tons of tea, by burning and burying it in relatively isolated places. However, this caused a new wave of protests by an already panicked and angry people who were alarmed that the tea would be burned and buried near their villages, fearing that the fumes would poison them. As a result, only 26.000 tons of tea could be burned and buried, and the rest has been kept in sealed depots in the Black Sea. The sealed depots did not solve the problem, since there have been several news accounts of these depots have been broken into, and the tea stolen and marketed illegally (Soner, 2005; Dündar, 2005).

The “Chernobyl effect” has resulted in a series of sensational rumors spread by the people who lived in the contaminated areas at that time, and stories that are still told by the cancer patients and their relatives in the hospital wards (Dündar, 2005). These people describe the color of water in the radioactive rain, as being a strangely grey or black. The cancer patients from the Black Sea and Thrace regions told me that after the radioactive rains, they found the swollen bodies of thousands of fish and frogs by the rivers. Some also described the eyes of their cows as being swollen and then exploding several days later, and that the cows stopped giving milk or reproducing. Although those stories are hard to prove now, they are well established in people’s collective memory, and the increase in cancer rates in later years has also led people to vividly remember and share them. There is still a common belief that the “Chernobyl effect” is one of the major causes of the increase in cancer rates in Turkey, and several epidemiologists, public health scientists, activists and journalists support this belief. However, few politicians, environmentalists and some medical scientists blame instead other types of environmental

and industrial pollution, as well as changes life-styles and smoking for the increase in cancer (Soner, 2005).

The political and medical authorities have brought their disagreements to the courts and media, and the ways in which the debate on the “Chernobyl effect” took place in such a public way affected the lay people’s conception of cancer and of the medical authorities. It has increased the gap between lay people and the medical and political authorities, both in terms of believing their explanations about the increase in cancer rates, and trusting their knowledge and expertise. Although the debates had a political and legal component in the 1980s, it has now become more social and personal, in accord with the recent changes in the social conception of cancer since the 1990s. Both the Chernobyl’s effects on cancer in Turkey and Ziya Özel’s case have helped cancer to become a public issue, which is discussed in the media on a daily basis.

**The Social Conception of AIDS in Turkey:** Although cancer has been the most visible and feared illness in the Turkish society since the 1980s, AIDS also became another major illness, which was discussed in public, in the late 1980s. The media first covered news on AIDS, with a focus on the foreign celebrities, who died of this disease, such as Rock Hudson and Freddy Mercury, and the first cases of AIDS in Turkey. The fact that the first known Turkish AIDS patients were a gay tour guide and a beauty pageant winner, who had AIDS while she was living in the US, has led to the common association of AIDS with marginal people who have close interactions with foreigners. The collapse of the socialist regime in the Soviet Union in the early 1990s, also led many Turkish people associate AIDS with the women who came from there to Turkey for prostitution, and the association with AIDS and foreigners has become stronger.

Although many Russian women who also came to trade goods and do jobs such as cleaning, baby-sitting, taking care of the sick and elderly to support themselves and their families, they were popularly associated with prostitution, AIDS and other sexually transmitted diseases (AIDS, 2005).

Like the social conceptions of epidemics of the late 19<sup>th</sup> and early 20<sup>th</sup>, adopting the “immoral, unhealthy and degraded” aspects of the Western life-styles is thought to cause AIDS, unlike cancer which was closely associated with the political and social problems in Turkey. Therefore, although the number of AIDS patients has increased slowly but regularly in Turkey and the disease affects different socio-economic groups today, it is still far from inducing the panic that cancer causes, because of its association with foreigners, marginality, sexuality and drugs. As I will describe in Chapter 5, the idealized self-image of the Turkish society as being family and community oriented, led many people to ignore the AIDS panic, which reached a global scale in the 1990s. There are only a few organizations which raise awareness about AIDS and AIDS patients’ social and psychological predicaments in Turkey, and their resources are more limited than those of the cancer organizations, which also have better access to the media (AIDS, 2005).

**The Social and Medical Conceptions of Cancer since the 1990s:** Since the 1990s, the social and medical conceptions of cancer have been directly related to the increase in cancer rates and possible reasons for that increase. The Turkish cancer statistics indicate a rapid increase in both the number of cancer patients and deaths from cancer between 1980-2001 (State Institute of Statistics, 2001, Dinçer and Firat, 1994). According to the data from the State Institute of Statistics (SIS, 2005), the numbers of

cancer patients and deaths from cancer more than doubled in the recent decades. In 1982, 11.372 cancer deaths were reported, and in 2001 this number increased to 25.540. As for the number of patients diagnosed with cancer, the increase was from 42.198 in 1978 to 98.507 in 1994 (SB, 1999). By the mid-1990s, cancer had become the second most prevalent cause of deaths in Turkey after heart disease, and this has led the Ministry of Health's "Section of War against Cancer" and cancer associations to organize more, nation-wide, educational campaigns for "cancer awareness" and the early detection of cancer through regular check-ups (SB, 1999).

Although the cancer statistics, widely reported by the media, alarmed the political and medical authorities, as well as the lay people, the health care providers and scientists question the statistics' validity. Some health scientists believe that the reported numbers are considerably less than the actual numbers, due to the hospital employees' reluctance to report the cancer cases, since they consider that task to be a burden in their long work hours. Moreover, the government does not enforce the rule. Since local authorities in small towns and villages, rather than doctors, often fill out the death certificates, most deaths from cancer also remain unreported in rural areas (Bilir, 2004). On the other hand, some health scientists and health care providers whom I talked to have more optimistic explanations for the increase in cancer rates, such as the improvement in people's health behaviors, which lead them to have more regular check-ups and make the diagnosis of cancer easier than it was in the past. Similarly, they argue that the average length of life has increased in Turkey since the 1980s, and that the disease is easier to detect medically in older ages. The explanation of easier detection of cancer thanks to the check-ups was reported by only three of the fifty patients I interviewed, who said that they had check-ups "on somewhat regular basis." Those patients had a higher socio-economic background

and enjoyed easier access to medical institutions, since they had close friends, who were doctors and nurses. By contrast, fifteen of the fifty patients told me that they visit hospitals only as a last resort, when they have a health problem that really bothers them, and for conditions that they cannot treat at home. As reasons for avoiding the hospitals, they cited their economic problems, the crowds and bureaucratic procedures in the hospitals, and harsh treatment by health care providers. Since the prevalence of cancer cuts across economic classes and social groups, there are also some people who benefit from smaller, less crowded private clinics and who do not experience the problems mentioned above.

Cancer, which was previously associated with urban, middle class and professional people in Turkey, has recently become common among the poor in the rural areas, as well as among recent migrants to the city from different parts of the country. Similarly, the previous association of cancer with the elderly people is no longer valid, due to the fact that youths and children with cancer have become a common phenomenon in the last twenty years. The public health specialist, Nazmi Bilir (2004) stated that the number of children with leukemia increased considerably and more people in their twenties and thirties were now diagnosed with lung or breast cancer. Bilir said that the general statistics do not yet reflect those changes, since the categorization by age was first applied to the cancer statistics in 1998. The recent prevalence of cancer in a wide range of social and economic groups makes the disease more dramatic to the extent that it is perceived as a “social epidemic” (Sontag, 1979). The fact that the causes of cancer are often multiple and hard to detect also contributes to its perception as a dramatic epidemic, which causes panic and anxiety. For instance, Nuriye, a breast cancer patient in her thirties, explained that before she was diagnosed she would “feel very uncomfortable and

scared,” when somebody uttered the word cancer, even if he or she does not refer to somebody she knew in person. She said that she would ask that person not to use that word and change the subject immediately. However, she added that having cancer has changed her, and that she wants more information on her cancer now, to the extent that her doctors seem to be surprised at her interest in the details of her illness and treatment.

Similar to the epidemics of late 19<sup>th</sup> and early 20<sup>th</sup> century, most patients and their relatives I talked expect medical and political authorities to fully collaborate in fighting against cancer. The patients also explain that they feel uncomfortable when the health care providers do not explain anything and disagree with each other about the patients’ diagnosis and treatment, which often occurs when the patients visit other doctors or hospitals for a second opinion. The unknown or contradictory facts about cancer, both in terms of the general cancer rates in Turkey and individual cases of patients, lead the patients to feel frustrated and scared, since they commonly see their illness as a “life and death matter,” as seven cancer patients said.

The health scientists and health care providers also differ from each other in terms of their ideological perspective in explaining the increase in cancer rates. Some of them subscribe to the explanations which blame the individual patients, such as the increase in smoking due to the permission to import foreign cigarette brands in the 1980s, and changes in the diet, which include an increase in the consumption of processed and fast foods. Others have a larger perspective, which focuses on living and health conditions, and they point to the environmental pollution due to unregulated urbanization and industrialization, and the Chernobyl effect as possible causes for the increase. Those explanations are often combined with psychological reasons, such as experiencing

stressful events or coping with stressful living and working conditions, or even having the typical unselfish, vulnerable and introverted “cancer personality.”<sup>27</sup>

The health scientists and health care providers I talked to also argue that the psychological factors have an indirect effect, by weakening the individual’s immune system. Some of them even argue that the earthquakes of 1999 and the economic crisis of 2001 also increased the number of cancer patients, since many people could hardly cope with the losing their loved ones and their economic losses. Four cancer patients referred to those events in the same way, and talked about how their sorrow weakened their body both psychologically and biologically, and led them to have cancer eventually.

The particular cultural constructions of emotional stress, sorrow and weakening of the body and soul as common reasons for having cancer are common both in popular and medical discourses. Although the patients relate emotional stress to cancer in a more direct way than health care providers, who emphasize the role of immune system, they are also glad to see that their explanation on the role of stress in having cancer is acknowledged by the health care providers. Gülsüm, a breast cancer patient in her fifties, explained that the medical staff in Güvercin genuinely felt upset when she told them that she lost her husband and her neighbor, who is also her best friend, in the earthquake, and that she felt relieved when a nurse said: “No wonder, you had cancer after all that trauma!” She thought that the health care providers there really understood her problems of loss and loneliness, and that helped her both to have a better interactions with them and a more effective treatment in general.

The disagreements among the health scientists and health care providers about the causes of the increase in cancer rates also stem from the fact that they lack a holistic

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<sup>27</sup> The association between cancer and stress will be also analyzed in chapter 4.

approach to the issues of health and illness, unlike the scientists and health care providers in the earlier decades of the Turkish Republic. Moreover, those explanations rarely explain the causes of individual cases of cancer, and there is no scientific data or research to indicate the influence of a particular cause (Aran, 2004). The patients often try to fill the gaps in their knowledge about why they had cancer and whether or how they will be cured by themselves, mostly through following the news on cancer in media and talking to other patients and their relatives. During the long-term treatment, where the patients learn about cancer and cancer treatment through various sources, they may eventually forget or mix the source of their knowledge. Therefore, the limited, and sometimes contradictory, knowledge that they learn from the health care providers may lose its relevancy for them, even though they accept the superiority of medical knowledge in principle.

In relation to the increase in the cancer prevalence, the news about this disease has also increased considerably since the 1990s. Many of the news items have been about “miraculous” treatment methods, or optimistic stories of cancer patients who were cured, which are deliberately aimed at challenging the typical association of cancer with death and alleviating the cancer panic. However, there is still a taboo concerning cancer in general, since mentioning that a particular person has cancer is still socially inappropriate, especially in the last stages of the disease or for the elderly patients. Even the health care providers talk about the disease only to relatives of the patient in such cases, and give a vague explanation to patients, such as “a problem in the bones.” The recent news on cancer patients in the media and how the cancer organizations attempt to challenge this taboo to a large extent by publicizing the cancer narrative of several well-known people. The support groups on the internet, which were founded in the 2000s, also include the

illness narratives of lay people, who are mostly urban, professional women, who have regular access to the computer and the internet. The rapid increase in the illness narratives in the media and on the internet has made cancer news less anonymous and more personal, by putting a face on cancer. The narratives often include the data about what the patients experience during their therapy, how they coped with the psychological and physiological difficulties caused by their disease, and how they “won the battle,” in accord with the war metaphors. Those narratives, even though they fail to represent the illness experiences of people from disadvantaged background, provide the patients, possible ways to talk about the private and personal aspects of their illness experience and relate them to the larger, public issues.

**Public Figures and their Cancer Narratives:** There are several autobiographical books, written by public figures and journalists in the 2000s, mainly for cancer patients and their relatives. Most of those books have become highly popular, and had a second or third edition a few months later.<sup>28</sup> These books are cheaper than many other non-fiction books and they are easily accessible (some are even sold in big supermarkets). Their popularity is also related to their personal, casual style and the authors’ avoidance of medical terminology. The books also have an emotional tone, which becomes apparent especially in the ways in which the authors connect the difficulties they had in coping with cancer to the other predicaments they have had in their lives. Most of these books have self-explanatory titles that highlight the fact that they are about the authors’ struggles with cancer. The translations of some of the titles are: “I live with Cancer”

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<sup>28</sup> The numbers of these books in one edition range from 10.000 to 50000, depending how well known is the author. The most well known of them is Filiz Akin and one edition of her book consist of 50.00 books.

(Sevindi, 2001), “How did I Beat Cancer?” (Kanat, 2003), “To Smile at Cancer” (Kalaycı, 2004), “After the Breast” (Irmakkesen, 2004), “Cancer Did Not Suit Me as Well” (Sağlam, 2005) and “A Hello to Life” (Akın, 2005). In the titles, there is also a deliberate attempt to use the word “cancer” in order to challenge the taboo status of the word. The authors often state that they wrote their illness experiences in order to provide guidance and counseling for other patients. They focus on how they kept their spirits up in order to get rid of cancer, and they convey the message “you can do just like I did, and be cured as well.”

Although the public figures’ strategies in writing about their cancer experiences keep intact their public image as “unusually strong and brave people” who know how to deal with major problems, they often fail to reach other cancer patients who have their own cancer stories. Several cancer patients I interviewed said that they read some of these books, but they did not find them that “all that helpful,” since the authors downplayed the economic and bureaucratic problems, which many patients experience, and glossed over the physical and psychological side-effects of medical operations, chemotherapy and radiotherapy. Those patients found it hard to relate to these authors’ experiences and “often too vague and general suggestions” for their own situation, since they think that the authors downplayed their high social status and economic power in sharing their illness experiences. Nevertheless, the authors of these books have become the public faces of cancer, and they dominate the coverage of cancer patients in the media, as did the cancer organizations’ charity events with public figures in the earlier decades. The authors also give talks in public conferences and seminars, and cooperate with cancer foundations and the Ministry of Health in their educational campaigns. Their messages

add a human touch, to what until recently have been, patronizing and threatening campaigns, often based on war metaphors, and neglecting the human element.

**The “Chernobyl Effect” in the 2000s:** The debates around the “Chernobyl effect” also became a public issue again in the 2000s, especially in terms of increasing cancer rates in the Black Sea Region. The cancer rates have increased considerably in both the Black Sea people, who remained in their region, and those who migrated to the big cities in the 1990s. Various support groups and organizations gathered around this cause both in the region and the big cities which received massive migration from the Black Sea in the 1990s (lazuri.com; Dündar, 2005). Through demonstrations in front of the major hospitals and the Ministry of Health, those organizations asked for an official apology from the Minister of Health who was in charge in 1986 for ignoring the long-term health effects of Chernobyl. The organizations also filed a complaint to the European Human Rights Court about several ministers from 1986 and today, including the current prime minister, Recep Tayyip Erdoğan, for underestimating the “Chernobyl effect” and for not taking the necessary precautions such as free screening in the Black Sea region and among the migrants (Radikal, 2004). The organizations and cancer patients in the Black Sea region also complain about the inadequacy of medical services there, and talk about the daily bus traveling from the “cancer villages” to the big cities, such as Ankara, İstanbul and Trabzon, full of cancer patients going to these cities for treatment (Dündar, 2005).

A popular ethnic-rock singer, Kazım Koyuncu, has become the symbol of the anger and frustration of the people against the Chernobyl effect and for the lack of political and medical interest towards the problem. Koyuncu organized a series of

concerts and press conferences for the benefit of cancer patients of the Black Sea Region, who are “neglected by the governments.” His representation of the “Chernobyl effect” case took a dramatic turn when he was diagnosed with cancer in April 2005, which caused his death in June 2005. Five thousand people attended his funeral, which was extensively covered by the media for several days, and many people claimed that his death not only shook the Black Sea region and the music world, but the whole country. His efforts to publicize the “Chernobyl effect” is continued by other musicians, artists and journalists from the same region, who organize concerts and gatherings to commemorate Koyuncu and Chernobyl, in cooperation with the Black Sea organizations and cancer foundations (Kaçar, 2005; Radikal, 2005).

Health scientists and doctors are also divided on the issue of Chernobyl effect, since some public health specialists and oncologists believe in it, others claim that, unlike the effect of smoking on cancer, it is hard to prove the Chernobyl’s influence on the increasing cancer rates statistically and medically (Köse, 2005). Turkish political and medical authorities prefer to emphasize the role of smoking in the increase in rates of cancer also since the connection between smoking and cancer is medically proved. A recent report by the “National Cancer Institute”, which is a part of the U.S. National Institutes of Health, explain the recent increase in lung cancer rates in Cyprus, Egypt and Jordan also with the increase in smoking and tobacco consumption, especially in younger ages (SEER, 2007). Nevertheless, the debates and demonstrations against the “Chernobyl effect” are noteworthy, since for the first time in Turkey cancer is associated with the large-scale activism of the non-governmental organizations, patients and lay people, as well as cancer organizations. The activism has also elicited public criticism and mistrust against the state and politicians, who neglected the effects of the accident on people’s

health, and against the health scientists who have downplayed the Chernobyl effect. Various environmental organizations also claimed that not only the Chernobyl accident but also industries, which pollute the air and water, the decomposition of old European ships in the Turkish ports, and cell phones and their receptor stations also cause the increase in cancer rates. These environmental concerns are covered extensively by the media and debated among doctors and medical scientists (Birlikseven, 1998; Adanır, 2005).

**Complementary or Alternative Medicine and Cancer Treatment:** The increase in the number of cancer patients and mortality due to cancer in Turkey, the debates around the reasons for this increase and the inadequacies of the Turkish medical system to prevent it, have led Turkish people to question the efficacy of medical and political authorities' "war against cancer." As a result, the alternative or complementary health care methods in cancer treatment have become popular. Those methods can be roughly grouped as the globalized new-age style treatments, such as yoga, reiki and aromatherapy, and the popular interpretations of "traditional," Islamic and folk medicine, such as healing through roots, herbs and prayers (Durmuş, 1993; Köktürk, 2004). While mostly urban, upper or middle class people benefit from the new age therapies, the other, "traditional" treatment methods are more widely used. Many people benefit from the alternative or complementary methods together with the biomedical treatment, and prefer not tell that to health care providers, thinking that they will receive a negative reaction, or that the hospital is not an appropriate place to talk about those methods (Topuz, 2003). The popularity of the second group of treatments and the increase in people who benefit from them are also related to the general critique of Turkish modernity and the recent rise of

Islamism, as I discussed in the first chapter. The Islamic scholars also relate the increase in cancer rates to the Turkish adoption of the degraded Western life style, which includes an excessive consumption of alcohol, cigarettes and fast food, having an “unhealthy night life” and forgetting the teachings of Islam. In doing so, it is said that they invite cancer into their lives, and unless they live a clean life again, no medical treatment can be effective. They also point to the necessity of praying for the cancer patients during their treatment, both for their psychological and physiological well being (Nurbaki, 1984; Durmuş, 2003).

Different explanations about why the cancer rates have increased and the popularity of alternative or complementary medical treatment methods reflect the recent pluralism in Turkish society, which has developed since the mid-1980s. The historical changes in Turkish society and in the health realm inform the social and medical conception of diseases, and that is especially valid for the conception of cancer in the last decades. In the following chapter, I will investigate the interaction between cancer patients’ illness narratives and social conception of cancer in Turkey today, with a focus on several themes that are raised by this interaction.

## **Chapter 4:**

### **Cancer Narratives: Main Themes, Cancer Patients' First Reactions to the Diagnosis and Social Interactions**

The main themes of the illness narratives of cancer patients are related to the social and medical conceptions of cancer in Turkey in various ways. The cancer patients often describe having cancer as a turning point in their lives, because the illness not only means a radical deterioration of their health condition for them but also changes their everyday lives and their social interactions. Acknowledging those changes and ruptures, which the cancer brings to the patients' life, is not easy for most patients, who want to believe and prove to their audience that their lives still continue as before. The efforts of patients in dealing with the changes and establishing continuity are informed by their conception of their identity and social position, which are primarily shaped by the patients' education, family, and their perspective on Turkish modernity. The patients emphasize the continuity in their lives also as a part of their efforts to cope with the psychological and physiological difficulties that are brought by cancer and cancer treatment. The patients' try to cope with those difficulties and re-establish a meaningful continuity in their lives often through creating a particular conception of good and bad patients, which reflects the categorization of health care providers that I discussed in the first chapter. The patients are aware of and try to adopt the health care providers' "good patient" category, even in their everyday lives outside the hospital, and they try to develop a general attitude towards their illness, which reflects the medical conception of cancer. However, those processes are often problematic, because of the discrepancies

between the patients' everyday interactions and interactions in the hospital, and between their view of cancer and its medical conception.

The main themes that appear in the cancer patients' illness narratives can be grouped into five categories: The earlier responses to the cancer diagnosis; changes in the social interactions of the patients; attitudes towards the urban and rural life styles; views on modernity, science and religion; and Turkish politics and world affairs. All those themes are interrelated, and they help patients to attribute a personal meaning and an individual interpretation to the social and medical conceptions of cancer. In this chapter, I will explore the first two themes in detail, with a focus on the interactions of the social, medical and personal views, and in the next chapter, I will discuss the three remaining themes. Before the analysis of the main themes, I want to describe the physical and social environment in Güvercin and SSK hospitals' oncology clinics in order to contextualize the discussion.

**The Physical Environment in the Two Hospitals:** As I discussed in first chapter, Güvercin (private) and SSK (state) hospitals are different from each other in terms of their physical environment and the personal interactions that take place within them. There is a comfortable and home-like environment at Güvercin hospital, which is created with large potted plants in the doctors' offices and waiting rooms, and decorative items such as wall calendars with the pictures of natural landscapes or baby animals, published by drug companies and distributed to the hospitals as gifts. In the chemotherapy section, there are various knick-knacks, such as baskets of dried flower arrangements, which are usually the gifts of patients. The large TV in the chemotherapy room and magazines in the doctors' offices and waiting rooms further the home-like

environment. Except for the radiotherapy section, which is on the basement, all the rooms in the hospital have large windows, which make them well lit, both by sunshine and electric lights. However, these “warm and friendly details,” as one of the nurses mentioned, are balanced by uncomfortable, plastic-covered chairs in the waiting room, the official warnings on hygienic rules and maps of human anatomy on the walls, which remind people that they are in a hospital.

In contrast to the “home-like environment” of Güvercin hospital, the oncology clinic of SSK, a labyrinth-like building with dimly lit corridors, offices, and waiting rooms, is full of people sitting on the chairs and on the floor, or standing, since all the seats are taken. The clinic was founded in 1974, and it has not been much renovated since then. The rooms, stairs and corridors also look considerably shabbier and less clean than at Güvercin. The waiting rooms of SSK are much bigger, and they also had uncomfortable hard chairs. There are rather old, faded tourist posters of Turkey on the walls. There are also fewer gifts from drug companies and patients around at SSK, since the doctors have a general policy of keeping those gifts at their homes in order not to “affect the serious environment of the hospital,” as one SSK doctor explained. There are also several small screen TVs in the waiting rooms, but the voice is off and they were hung high, close to the ceiling, so that people rarely watch them while waiting. Unlike Güvercin, the oncology clinic has wards, where some patients stay for several days. The walls of these wards are bare and there is no other furniture there except eight beds and four small tables with drawers in each ward. Doctors’ offices are smaller and have less furniture than in Güvercin. They also look more official and medical with the large, doctor’s desk that dominates the room, and on their walls there are work-related charts

and short notes on post-its related to the work shifts, as well as official warnings on hygienic rules and maps of human anatomy.

**The Social Environment in the Two Hospitals:** The cancer patients generally describe their social interactions with the health care providers, who work at SSK, as formal, brief, tense and stressful. However, the patients at Güvercin hospital described their interactions with health care providers, as warm and emotional, adding that they “really care for their patients,” as three patients observed. The health care providers at Güvercin speak softly and more affectionately to the patients, and take time to comfort them when they express their concerns. Two male doctors, who were also on the Board of Directors of the hospital, were generally considered to be “the father figures” there, and they were treated with respect both by the patients and other health care providers because of their age and professional experiences. These two doctors were also praised for the meticulousness of their paper work, and ability to solve bureaucratic problems about the patients’ file or insurance. As one doctor explained: “These two doctors are the founders of the whole system in this hospital, so no one knows how its system works better than them.”

There was also a female oncologist in the chemotherapy section of Güvercin hospital, whose interactions with the patients differed from those of other health care providers in the Turkish hospitals. She is from the Turkish minority in Bulgaria, and she migrated to Turkey in the 1980s as a result of the Bulgarian campaign against that minority there. She argued that the medical education in Bulgaria was much better than the medical education in Turkey, since it had a “humanistic approach,” which emphasized the “well being of all human beings in every possible way.” Among all the medical

employees whom I have met at Güvercin and SSK, she had the closest interactions with the patients and their family members. She spent considerable time and effort in order to comfort the patients and explain different treatment methods and the biological details of cancer. Three of her patients of hers argued that she differs from all the other people who work in the hospital, because she is “European.” According to those patients she acquired “the European mentality” in Bulgaria, and that is why “she treats the patients as real human beings, rather than looking down on them” like the other doctors they know. Altan, the retired architect and colon cancer patient, said that she was so good to him throughout his treatment that he began to view her as an older sister. He said that she was equally sad with him and his wife when his medical tests results were not as good as they expected, and equally happy when his treatment gave positive results.

Similar to the Altan, both doctors and patients at Güvercin often described health care provider-patient interactions in kinship terms, such as doctors’ being a father, an older brother, or a nurse being an older sister. The patients seemed to internalize the typical health care provider-patient hierarchy in the Turkish hospitals, by using the terms for older family members for these people, who were younger than them in some cases, because of their professional authority, medical knowledge and expertise. However, the description of health care provider-patient interactions with kinship terms also indicates an emotional and intimate bond between the two parties, which is quite unusual for the other hospitals in Turkey. Metin Aran, one of the founders of Güvercin hospital and the two elderly doctors on the Board of Directors, explained that when designing Güvercin hospital, they modeled it after the cancer centers in the United States and Europe. However, since they had a disagreement about having a psychologist in the hospital on the Board of Directors, the board decided that the doctors and nurses should instead

provide the necessary psychological help for their patients when they had concerns about their illness and cancer treatment.

The radiotherapists at Güvercin did not share the Board of Directors' decision on psychological help and support. In fact, there was a tension between the chemotherapy doctors and radiotherapists, who blamed that the chemotherapy doctors were “too warm to the patients.” The female doctor, who migrated from Bulgaria, often became the main target of these criticisms, since she was spending the most time with patients. Her origin was also an issue for the radiotherapists, who believed that “all these doctors and nurses came from Bulgaria, and tried to replace the Turkish doctors and change the age-old traditions in the Turkish medicine.” A male radiotherapist also criticized the female doctors and nurses in the chemotherapy section at Güvercin, for accepting all the “silly decorative items” that these patients brought them as gifts in order not to offend them. Similar to the doctors at SSK, he said that displaying those items broke the rules of hygiene as well as harming the necessary seriousness of doctor-patient interactions. Another radiotherapist thought that the evil-eye and other charms, such as garlies in porcelain, hanging on the walls of the chemotherapy section were inappropriate, as they did not suit that hospital, which should be the “cradle of science and medicine.” However, the doctors in the chemotherapy section said that they liked all these decorative items, and would keep them since they make the rooms more cheerful and comfortable both for the health care providers and patients. The doctors on the Board of Directors also supported the position that all those items made the patients feel better when they were having their treatment.

The tension between chemotherapy doctors and radiotherapists also stem from the fact that two radiotherapists also work in another private hospital in the afternoons. One

chemotherapy doctor explained that she approves the new law that prevents doctors, who work in a hospital, to have their private practice, but she also found the law inadequate, since it still allows doctors to work in two hospitals. She said that the fact that their doctor should leave early to work in another hospital causes problems for the patients: “By two o’clock in the afternoon, our radiotherapists begin to rush and try to get rid of their patients as soon as possible since they have to be in that new, private precisely at three o’clock. After 2.30, they stop taking care of the patients even if those patients had an appointment and waited for forty minutes! They just tell them to schedule another appointment, and I think it is a shame since it shows that they give priority to their jobs and patients in the other hospital, possibly because they are paid better there.”

The conflict between the two sections also stems from the gender issues between the two sections, since it mainly arose between two female doctors in the chemotherapy section and three male doctors in the radiotherapy. The doctors who criticized the decoration of the chemotherapy section also believed that medicine is traditionally a man’s profession, and women, if they insist on being doctors, should specialize in a “lighter branch”, such as dermatology which did not include night shifts and surgery. They also said that the job of the female doctors in the chemotherapy section was much easier than theirs, and “they spent their time in gossiping and watching TV with nurses and patients,” which also disturbed the accepted hospital hierarchy. In response to those criticisms, the female doctors of the chemotherapy section said that the male radiotherapists are unnecessarily strict about doctor-patient hierarchy. They added that the doctors on the Board of Directors were also on their side when they had open conflicts with the radiotherapists, so that the radiotherapists became “an unpopular minority” in the hospital. I made the same, since the doctors on the Board of Directors often dropped by

the doctors' offices in the chemotherapy section to chat with them, and generally ate at the same table with them in the hospital's cafeteria. The patients seemed to be unaware of this conflict, probably since many of them evaluated the relatively distant doctor-patient interaction in the radiotherapy section as normal or ordinary. Therefore, in their evaluation of the interactions between health care providers and patients at Güvercin hospital, they mostly emphasized the "unusually warm" ties that they had with the doctors in the chemotherapy section.

Since they spent more time with, and had closer ties with the patients, nurses were the natural allies of the chemotherapy doctors in the conflict with radiotherapists. The nurses, all female, often joined the chemotherapy doctors when they criticized the radiotherapists, even if they did not express their negative views openly, because of the professional hierarchy. The patients said that nurses were even more approachable than the doctors in Güvercin, since the patients could ask them the questions that they did not dare to ask the doctors. Five patients indicated that they preferred to speak about the side effects of their cancer treatment to the nurses, because they believed that the doctors were already too busy with their cancer treatment. Both Okan, a lung cancer patient in his thirties, and Selma, a uterine cancer patient in her thirties, explained that they also felt more comfortable in discussing the alternative treatment methods, which they used, with the nurses, since they did not want to make the doctors angry and disappointed with such discussions. Selma explained the reason for this preference: "The doctors spend all that effort to diagnose my illness and treat it. They use the latest technological equipment and scientific methods for that. So, I just feel too embarrassed to tell my doctor that my neighbor, who is also a cancer patient, recommended that herbal tea, or root extract, and I would not ask him what he think about these remedies... Moreover, I can never find the

right time and place to ask my doctor even the basic questions about my illness and treatment ... The nurses spend more time with us and I feel less intimidated to ask them any questions.”

The nurses were also the mediators between doctors and patients, especially in the cases when they thought what the patients tell them was important, or “worth-reporting” to the doctors. A nurse who worked in the chemotherapy room described her role as a mediator: “Since we spend quite a lot of time with the patients, sometimes they feel too close to us and tell us whatever they think or do about their illness. Some of them can be really absurd things, like carrying *muska*<sup>29</sup>, and the doctors have absolutely no time to listen to all that.... However, if, as a nurse, we think that the patients harm themselves by using a particular healing method, we have to report to the doctors, in a nice way, i.e. without making them angry.” Several nurses also explained that their duty was also to help doctors to wind down after seeing the patients by engaging in small talk with them. This often meant exchanging comments on the patients and people, who accompanied them, about what they wear, say or do, especially if this challenges the hierarchical interactions between health care providers and patients. For instance, when a breast cancer patient’s husband sat in the doctor’s office with his legs crossed while talking to the doctor, the nurse told the doctor that he was a bit “Too comfortable and relaxed.” The doctor agreed with that comment and she laughed about it with the nurse.

Compared to Güvercin hospital, the social environment in the oncology clinic of SSK hospital was much more tense and stressful. There are many more patients at SSK hospital than in Güvercin and most patients were poorer, since the SSK insurance was

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<sup>29</sup> The charm-like, triangle-shaped leather box that contains prayers written by a *hoca* and that is often carried as a necklace to bring long and healthy life and to protect the person who carries it against evil.

provided for the unqualified and low-rank workers and people who were retired from such positions. Partly because of the crowd of patients and people who accompanied them, and excessive bureaucratic procedures, the interactions between the health care providers and patients were often impersonal and aggressive. Only the patients who had to stay in the wards of the hospital for several days, since they could not afford to go back home in-between treatments<sup>30</sup> said that they became each other's family since they did not have many visitors. However, in contrast to the several patients who described all the people in Güvercin hospital as "one big family," the patients who regularly visit SSK hospital often emphasized that they feel anonymous and as "yet another burden" for the health care providers.

In order to feel less anonymous and become more familiar with SSK's bureaucratic procedures, the patients develop certain strategies on whom to socialize with and whom to ask for help while waiting to see a doctor. Waiting in order to visit the doctor for the examination or for a bureaucratic procedure, such as having the doctors' signature on the patients' file or prescription, may take several hours, and it is an important part of the cancer patients' experiences at SSK hospital. While waiting, the people often stare at each other in order to be able to find someone to speak to. Filiz, who was a secretary in a small private firm and a breast cancer patient in her forties, said that since the patients were often given numbers they would sit down while waiting. She usually spends the first half hour of waiting by doing the necessary phone calls for her work from her cell-phone. Then she looks around to see whether she could chat with

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<sup>30</sup> Some patients at SSK could not afford the ticket for the public bus in Istanbul, although they needed to visit the hospital for several days a week. There were also few patients who did not have any family member, who could take care of them, in their house. However, most patients in the wards were there, because they had a physical condition, which prevented them to go out of the bed or which should be medically supervised during their cancer treatment, such as high blood pressure and diabetes.

someone: “Most people who come here are the villagers, you can understand from their large pants, vests and old-fashioned shirts as well as their thick dialect. Some of them are in Istanbul may be for years, but they remained villagers.... If I ever talk to them, they will whine about their cancer and their treatment. Those types make me even more depressed. I look for someone who is around the same age with me, and who dressed up as smartly as I did, since many housewives are not that different from villagers too... In that crowd, I can manage to find one or two people with whom I can chat for all that time, and I even manage to be friends with them sometimes. I also learn quite a lot of things on cancer and different ways of treating it in these conversations.” The waiting crowd eventually formed small conversation groups, and the people in these groups often seemed to share similar socio-economic characteristics.

Most male patients and their relatives also formed groups who went out together to have a cigarette break and chat in the small garden, even in the cold and snowy weather, even though some of these male cancer patients had lung cancer. I first thought that the lung cancer patients’ smoking and being outside in a cold and snowy weather without a coat could be acts of resistance against the doctors who told them to give up smoking and to avoid the flu. However, when I talked to some of them I realized that they smoke in the cold, since they associated their cancer with death, and believed that they would not be cured even if they completed their treatment successfully and did everything that the doctors told them to do. Ahmet, a lung cancer patient in his forties, who spent all his waiting time by smoking outside, said that he did this from a lack of hope about the possibility of being cured and living for a long time: “I know that despite all the efforts of doctors in order to treat my cancer, this illness will kill me eventually. What can you do? This illness is already spread out all over my body and I feel very sick for months...

Although the doctors tell me not to smoke and stay in the cold, smoking in the garden of SSK and talking with the people who are in the same condition with me, are the two of the very few things I enjoy. May be if I will not do these I will live for one more month, but what is the point of living like that, without doing things you like?”

Because of the long hours of waiting and stressful bureaucratic tasks, the tension between the health care providers and patients or the people who accompany them lead to verbal arguments around 8-10 times a day, which may last up to 10-15 minutes. As soon as these arguments become physical (mainly pushing or hitting each other), the people around them often rush to separate the fighting people, but the verbal fight often goes on for a while.<sup>31</sup> The arguments take place mostly because of the patients’ missing papers or signatures, and the patients who forgot their numbers or who did not hear when they were called to the doctor’s office. Although the patients keep seeing the same doctors, their interactions with these doctors were more distant than the doctor-patient interactions at Güvercin. A male doctor in his thirties who worked at SSK, explained that distance in terms of the large variety in the socio-economic background of the patients: “Everyday we have a whole panorama of Turkish society here. We have people from all the cities and regions of the country... In a typical day, I have to see 30 patients a day, may be it is even more. In these conditions, I have only around ten minutes to go through the file of the patients, to examine and talk to them. Still I try to do my best in that limited time, but most patients are needy. Probably the other patients tell them that if they ask a lot of questions they receive more attention from the doctors. However, some of the patients are just too ignorant to ask meaningful questions about their illness. They take our time with unnecessary questions like ‘why don’t you prescribe more medication to me since I

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<sup>31</sup> An example of such a fight, the fight between Abdullah and his doctor, is discussed in the Chapter 1.

have a phase three-cancer?’... You feel like it is a waste of time and you are being unfair to the other patients who were still waiting.”

Several doctors and nurses also argued that working at SSK damage their professional career, since they can rarely find time to do research and present papers at conferences. One doctor complained about the fact that his career is reduced to taking care of patients while his colleagues who work in private hospitals present and publish brilliant papers. One nurse said that they are luckier than SSK doctors in that sense, since they spend more time with the patients and have a better chance to hand them out surveys. However, she also added that their research takes longer than that of nurses in private hospitals, because of the large number of patients that they have to take care of. When I asked the medical staff at Güvercin about this issue, they also confirmed the complaints of SSK staff.

Yılmaz, a lung cancer patient and an active union member, believed that because of its crowd, bureaucracy and ever-present tension, SSK hospital had created “an SSK culture,” which everybody in Turkey is familiar with. Accordingly, the patients come to SSK without much expectation from the health care providers. They are already stressed even before entering the clinic, because of all the problems that are waiting for them. In her book on her cancer treatment, Sibel Kalaycı (2004), a journalist and a breast cancer patient in her late twenties, wrote that SSK hospital makes the patients even unhealthier rather than healing them, with its long waiting lines and problematic bureaucracy. She also had part of her chemotherapy session in the Güvercin hospital, which she described as having the comfort of a five star hotel compared to SSK. She also mentioned that, in contrast to SSK, the health care providers in Güvercin cared about her fear from the

needle, and they brought a stuffed pink panther toy before her first chemotherapy so that she could play with it in order to distract herself.

The patients also admitted that the crowd of patients at SSK affects the doctors' attitude towards them negatively, but nevertheless they also believe that the doctors have to be more humane. Okan, a lung cancer patient in his thirties and a research assistant in the psychology department of a private university, argued that the SSK doctors' attitude did not suit the prestige that is attributed to their profession: "We all know that the doctors have one of the toughest jobs in the world. They have to learn all that medical knowledge and always keep that knowledge in their mind when they deal with life and death issues of patients... However, I also believe that the doctors at SSK forget that they deal with *real human beings* with emotions, and that stems from the fact that they never really learn psychology in medical school...On the contrary, all that tough medical education and professional experience led them to have serious psychological problems. They are enormously stressed all the time, and all they can do is to project all that stress to the poor patients!" Doğan Pazarcıklı (2002), a former mayor, who wrote a book on his experiences in various public hospitals, where he accompanied his cancer patient wife, compared the state hospitals to barracks and prisons, because of the hospitals' cold and tense environment and the strict hierarchy between medical employees and patients. Seven patients at SSK commented in the same way, pointing out that the impersonal and hierarchical interactions with doctors intensified their worries on cancer and cancer treatment. Although they had low expectations of personal care from the doctors at SSK, they still "felt alienated by the lack of doctors' interest in them," in Feriha's words.

As in Güvercin, the patients said the female doctors at SSK were more concerned about their patients' medical, psychological, bureaucratic and economic problems than

the male doctors'. Several SSK patients, most of whom were women, especially singled out "the feminist doctor," who is in her thirties and "really cares about the patients" in Esma's words. Esma, a breast cancer patient in her thirties, explained why that doctor is different than the other SSK doctors: "I think she is idealistic because it has been only few years she started to work here... I hope she will not become weary like the other doctors here in the future though, but I also think her character is different. Even by her looks, she stands out, with her really short, blond hair and brisk walk in the clinic. I believe that she is genuine and she really cares about my problems. She helped me a lot in solving some of my bureaucratic and payment problems, and she gave me good tips about how to tell my husband that they have to remove my breast. However, I heard from the other patients that she is not as nice as to the male patients because she is a feminist, especially when she thinks that they speak or think in a macho way (She laughs)." When I talked to that doctor, she told me that the patients are right in viewing her as a feminist and that she is active in several feminist organizations. However, she also emphasized that she treats all of her patients equally, no matter they are women or men, and blamed the other doctors, who treat the patients with low socio-economic background worse: "All the doctors here will deny it, if you openly ask them, but you can actually see how the expression on their face changes immediately when a patient, with a modern, urban look comes into their office. Their face immediately lights up and they become more polite. Of course, those kinds of patients, who have a similar background with the doctors, are rare here."

The patients also described the nurses at SSK hospital, as being less friendly than the nurses in Güvercin and other private hospitals. I also observed that the nurses often engaged in arguments with the patients and the people who accompanied them at SSK

hospital. According to Esra, a breast cancer patient in her twenties, the nurses at SSK always took sides with the doctors and against the patients when there was a problem: “It is as if they are the bodyguards of doctors. They, consciously or unconsciously copy the attitude of doctors. If the doctor is good to the patients, the nurses are also warm and friendly towards them, but if there is a problem, first thing they do is to blame the patient.”

**Earlier Responses to the Diagnosis:** I chose earlier responses to the diagnosis as my first theme, since the illness narratives of most patients start with an emotional account of the moment, when their doctors told them the diagnosis, and their first reactions. Most cancer patients described having cancer as a major turning point both in terms of their health condition and everyday life. 28 out of 50 cancer patients emphasized that they were perfectly healthy before they were diagnosed with cancer, and most of these patients went to the hospital just with “minor complaints,” such as stomach ache. Those minor complaints led to medical tests, which eventually indicated that they had cancer. A typical example of this is Selma, who is an ovarian cancer patient in her thirties. Selma explained that she had never suffered from any health problems before, that she just had flu, which is the most typical illness, a few times in her childhood, and that she had perfect teeth with only one tooth that was filled.

Selma’s first cancer symptom was a sharp pain during menstruation. She had her first menstruation at age 13, but for 20 years she did not consider the pain she experienced to be serious, since all the women in her family had the same type of pain, and her menstruation was regular. Only when she had pain *after* her menstruation and in different parts of her body as well, did she think that this problem could be serious

enough to see a doctor. Both having a “healthy past” and not suspecting anything wrong in her reproductive system intensified the shock that Selma felt when she learned that she had a tumor in her ovaries, “as big as an orange.” Selma said that she did not suspect much from pain during menstruation, because of the “general view” that the menstruation should be painful and messy, and she heard this both from the women in her family and the girls in her school while she was growing up.

Most patients, who see cancer as a turning point in their health conditions, also consider “health problems” to be the problems that require them to visit hospitals, rather than the pains and aches that they can cure by taking pills at home or by drinking herbal teas. They prefer to cure their health problems at home by themselves or with the help of people who are close to them for a long time before they realize that the problem is serious and needs medical assistance. Yılmaz, a retired factory worker, but still an active member of worker’s union in his late forties, argued that the hospital is the last resort for him and for the people who have the same socio-economic background with him. Yılmaz said that a person becomes sicker at SSK hospital, because of the bureaucratic struggles, waiting for several hours in the crowd, and getting “snubbed by the health care providers.” He said he hated every time he had to go the hospital so that he avoided going there “to the point of neglecting his health problems.” Yılmaz described himself as a generally healthy person, except for having tuberculosis when he was 17 years old, and later on, a kidney problem that doctors failed to explain. More than thirty years later, he began to have aches both in his lungs and kidneys, and when, after several months, these aches became “unbearable”, he visited the hospital with the fear that his tuberculosis was recurring. However, he was diagnosed with lung cancer, and several malignant tumors were also found in his kidneys.

In the course of the interviews, most patients said such things as “I was perfectly healthy in the past,” “Even when I was a child, I never became sick,” in answer to my initial questions about their health before having cancer. However, when I asked for further explanations with more specific questions, such as “How about more minor health problems such as flu or diarrhea, did you have these illnesses in the past?” or “So you never had to visit hospital in the past...” Then the patients mentioned health problems that often contradicted their initial statements on their perfect health condition in the past. The initial response provides a dramatic “before and after” contrast and emphasizes the diagnosis as a turning point, where people start to live as “cancer patients.”

The signs and symptoms of cancer are also rather subtle, which makes the diagnosis more unexpected for the patients and their families. For instance, Altan, a retired architect in his sixties, went to the hospital because of a minor problem of indigestion as a result of his wife’s insistence, thinking that “a few gastro-intestinal pills” could cure his problem, and was then diagnosed with colon cancer. The fact that cancer patients considered themselves to be healthy people before their diagnosis, avoiding hospitals until they have a serious problem, indicates both the exceptionality of having cancer in their lives, and the problematic aspects of the hospitals in Istanbul. Only three of the cancer patients said that they had regular medical screening to detect cancer, and this small group consisted of two female breast cancer patients who have several breast cancer patients in their families, and a male lung cancer patient who deals with PVC (polyvinyl clothing) in his workshop, which he considers to be causing lung cancer. Seven female and two male patients said that they occasionally visit doctors for cancer tests, and when they do not have time, they may skip those visits for 2-3 years. Not surprisingly, the people who have regular or occasional medical tests are from middle or

upper class-background and have regular income as well as health insurance. Health care providers view them as “conscientious patients” who should set an example for the other patients as well. Except for two, who were at SSK hospital, the entire group had their treatment in Güvercin hospital, and all of them also consulted other doctors in private hospitals in İstanbul for further comments on test results or for urgent medical tests.

Six cancer patients said that they realized that they had cancer through reading the reports on the medical tests, and the talks they overheard among the health care professionals before the doctors told them the diagnosis. Interestingly, the “realization of having cancer” takes place by looking up medical terms in dictionary, on the internet, or by an “intuition based on previous experiences in hospital” as in the case of Yılmaz who was earlier hospitalized for TB. Ayşe, who works as a human resources manager in a firm and is a breast cancer patient in her late thirties, explained that when she got her test results, she underlined every “Latin word” on the papers and checked them on the internet. She then took the reports to her doctor, thinking that her doctor would not provide her with a detailed explanation on her health problems. She added: “When I figured out that *breast ca-phase 3* means that I have breast cancer that is also spread to the lymphs under my arms. This gave me a sense of control over the situation. I have felt much better throughout the therapy and in my interactions with doctors. Since then, I look at the test results of the other breast cancer patients in the waiting room if they ask for help, and explain their reports in order to help them to understand their condition better.” Yılmaz felt that he had something more serious than TB from the solemn face of his doctor, who looked at his test results, and the indirect manner that his doctor had when he said, “you have a serious health problem, but it is not incurable.” Yılmaz answered his doctor: “Do

not push yourself too hard in explaining what I have. I know what I have. I know that I have cancer.” His doctor confirmed him by saying: “Yes, unfortunately you are right.”

The emotional tone of the doctors when they give the diagnosis to the patients is also important in shaping the patients’ reactions, and in the rare cases when a moment of mutual empathy and understanding can be established between doctor and patient, the two people can establish a better interaction throughout the whole treatment. Altan explained that in the initial tests the doctors found a tumor in his body but they also needed several other, more specific, tests to locate it. After these tests, when he was waiting for his doctor in a private hospital, the doctor entered rapidly with a smile on his face and said: “I have very good news for you, finally we were able to locate where your tumor is!” Altan really liked this “no-nonsense and correct” attitude and internalized his doctor’s optimism by looking at his cancer as a “puzzle that will be solved with a hundred percent scientific approach.”

In contrast, Ayşegül, who is a breast cancer patient in her early thirties, became really upset when she learned the diagnosis, but she felt better when she realized that her doctor in the Güvercin hospital “shared her sorrow fully.” Her doctor called her at night when she was preparing dinner with her husband. He told her: “I wanted to tell you the news when both you and your husband are at home. I am very sorry to say that our suspicions were valid, you have breast cancer. It is so unfair that this happens to you when you are so young and just married. But because of all this you must be full of hope and energy, so your chances to beat this illness are really high.” Ayşegül said his doctor’s sincere and emotional talk was touching for her, and she felt special because this doctor took time to call her at home. I interviewed Ayşegül three months after that phone talk,

which made their interactions “more personal and better” throughout the whole treatment, which was still due at that time.

Some patients also evaluate a seemingly negative attitude from doctors as beneficial, as in the case of Selma, who felt like crying when she received the diagnosis from her doctor, whom she described as a “father figure”, who may scold his daughter, but still would like her. Seeing that she is about to cry, her doctor teasingly told her: “Girl, don’t ever shed those tears in front of me, you waited for years to visit a doctor for your problem, then you start to cry when you learn the result of your negligence. I know that you are young, but you are old enough to bear the consequences of your mistakes, and you must know better than crying like a little child whenever you are upset.” His words felt like “an ice-cold shower” or a “big slap on the face” to Selma, who always considered herself a tough woman, in contrast to many teary-eyed patients she had encountered in the hospital, and gave her the toughness she needed in coping with cancer. The doctor Selma talks about had a reputation at SSK hospital for his harshness, and many people avoided him as much as they could because of this. In addition, because of this reputation, Selma was proud of herself and her “unusual toughness” in her ability to deal with this doctor’s sarcasm for more than one month before she was transferred to Güvercin hospital. She said that she understood that doctor, and his scolding felt more like teasing, but she also became immune to any type of harsh attitude when she left SSK hospital.

**Living with the Diagnosis:** As a part of the earlier reactions to the diagnosis, the cancer patients also learn to live with cancer, and that is a gradual and problematic process. Patients learn not only that they have cancer, but also how they cope with that

major problem in their lives. The patients have two different strategies in coping with the diagnosis, which are also informed by their socio-economic status and the health care providers' conception of "good patients." Those strategies are learning as much as possible about cancer and following closely the detail of their cancer treatment, and avoiding the issues of cancer and cancer treatment to the point of denial. Nine cancer patients mentioned that they felt better when they learned about the diagnosis and the treatment plan, thinking that they knew, at last, what their health problem is and how to solve it. Those people also did extra research and followed the news on cancer, since they believed that the doctors can give them only a limited amount of data, and the more they know about it the more they feel in control of what is happening. They stressed that they always want to be in charge of their life, and they managed to do so thanks to their inner strength. Those are mostly middle and upper class, young professionals who grew up in the city, and six of these people are women. Most of their medical treatment took place in the Güvercin hospital, and they only went to the SSK to get free medication and further consultation with doctors.

Altan is an extreme example of that group of patients, with his "cancer diary," which consists of the photocopies of his test results, notes on the doctors' comments and day-to-day evaluation of the side effects of his cancer treatment. He decided to keep this diary one day after his doctor told him the diagnosis in order to be able to keep track of his treatment and the changes it would bring to his life. Altan was proud of his diary, which he described as detailed as a sea captain's travel diary. He argued that civilized and well-educated cancer patients should do their best to learn about their illness, as opposed to the ignorant patients who do not have much education who falsely believe that if they avoid learning more about their illness, it would not affect them much.

In contrast, eight cancer patients said that they do not want to learn anything extra on cancer and cancer treatment after they learned the diagnosis, since they believe that the doctors' explanations are enough for them and any other information on these issues is less valuable. The age range of these people varies between 52 and 78. They come from a lower-middle class background, do not have access to internet and have limited access to visual and written media. Six of these patients were treated at SSK only, and since they had economic problems, the SSK hospital was their only chance for treatment with their insurance. Ayla, who is a breast cancer patient and housewife in her fifties, said that her doctor, who examined her body and her tests, would know her condition best and any other news on cancer would be just empty words. Ayla explained: "Six years of medical education and even some more years of specialization on cancer treatment, make the doctors the true experts on the condition of the patients like me...So, even if the doctors do not talk to the patients in the public hospitals because of the crowd, I am sure that they give us all the information we need."

Gülten, who is a breast cancer patient in her sixties and who works with her husband in growing cut flowers, said that the more she learns about cancer the more she feels pessimistic, and that is why she avoids this topic even while talking to her family members and friends. She said: "I think and talk enough about cancer when I am in the hospital, so when I am out, I prefer to do other things, such as going shopping and chatting with my friends, and watching fun TV shows. Even if my friends sometimes try to discuss my illness with me, I cut them short by saying, please let's talk about something more fun." Although Gülten said those things to show that she copes well with her illness and that her illness did not change her life that much, the psychologists warn against avoiding thinking and talking about cancer as this can have negative

consequences. The psychologists, Serra Müderrisoğlu and Pınar Serbest (2004), who are specialized in working with cancer patients in Istanbul, say that their biggest problem is that the patients with a disadvantaged background avoid talking about their illness to the point of denial. Müderrisoğlu and Serbest add that they like to act like a strong person by repressing their negative feelings, even if they chose to consult them, as if they want to prove to the psychologists how well they cope with cancer. Serbest mentioned that in those cases, it often takes the patients several sessions “to open up and show what they really have inside their thick shelves.”

That reluctance may be also related to the fact that consulting a psychologist is still not very common and generally associated with having serious psychological disorders, as I discussed in Chapter 3. Only three patients stressed that all cancer patients should have a professional psychological help in the hospital where they have their treatment. The three patients indicated that this is the case in Europe and the US, where the professional psychologists let the patients talk about their problems in order *to solve* their problem in contrast to most Turkish patients’ “sharing problems just with family members and close friends” that make them feel better *only temporarily*. These three patients, who had their treatment in Güvercin hospital, work or have retired from white-collar jobs, and belong to the upper-middle class. Among them, only Selma said that she consulted a psychologist for two months right after she learned that she had cancer, and Ayşe said that she might think about it when she would lose all of her hair after more chemotherapy sessions and would not get used to it. However, the other patients I interviewed stated that they do not need any psychological help, even though several of them talked about the psychological problems that really bother them, such as fear of death. Those patients stressed that they may have psychological problems, but they are

strong and sane enough to deal with them, and they are “not that crazy” in Lerna’s words, to ask for a professional help.

Several doctors also complained about the fact that many cancer patients do not want talk about the specifics of the illness. The health care providers evaluate the patients’ avoidance and denial as having a negative impact on patients’ efforts to cope with cancer. They also emphasize that the “good patients” are the ones who can talk about relevant issues on their illness with them, even during a brief examination process. However, six patients said that they do not feel particularly encouraged to talk about their illness by the doctors and nurses, who often interrupt them and ask them questions back to back “as if they are in an oral exam,” in Selma’s terms. The patients also know that they have to provide short answers, knowing that many other patients are waiting to be examined, especially at SSK hospital. Therefore, they give brief answers to their doctor, even though they know that they have to talk more about their illness in order to have a better, more fulfilling interaction both for the patients and health care providers.

Moreover, some patients stress the positive aspects of denial, such as Sabahat, a retired employee of a bank and a breast cancer patient in her fifties. She said: “Since the beginning of my therapy, I am in a denial phase that the doctors mention. I go out for shopping or even have brief trips to tourist places with my friends. I keep telling my friends to talk about fun things instead of cancer, even if they ask about my health.... I am glad that I live as if I don’t have cancer.” It is interesting that Sabahat internalized the medical terminology “denial phase,” but interprets it in a more positive way. GÜlsüm, a breast cancer patient in her fifties, also stressed that she did not look as someone with cancer, since she had a wig that looks as pretty as her natural hair, she dressed up nicely and had perfect make-up. She said that she felt much better when she looked good, and

she particularly enjoyed shocking people who complimented her on her looks by telling them that she was having an aggressive cancer treatment. She stressed that she was denying that she had cancer not only by her social life, but also by her good looks.

The patients at Güvercin often paid attention to use same the terminology with their doctors and nurses when they talked about their illness and treatment, since to speak the same language with them is important,” in Altan’s terms. In contrast, most patients at SSK, who have much less and more problematic interactions with the medical staff there, do not show special effort to use a medical terminology. Hamiyet argued that she did not feel obliged to please the doctors and nurses, who took care of her, by using their words that she could not even pronounce properly: “I do not understand all those medical words. I do not understand them, and I can hardly remember or say them. So, why will I try to use those words, instead of my own words?... The doctors will probably laugh at me when I use them in a wrong way. Their attitude towards me is not particularly nice, so why would I spend an extra effort to be nice to them?” However, the word “denying” is also often used by the patients at SSK, even though it has different connotations for them.

Arthur Kleinman (1993) interprets patients’ “denying cancer” as a form of resistance against the biomedical authority, whereas Linda Hunt (2000) considers this attitude one form of living with cancer. Turkish cancer patients who stress living as if they do not have cancer is also related to re-establishing a sense of continuity caused by the rupture that cancer brought has to their lives, so it may seem more in accord with the Hunt’s argument in the first instance. However, it is also an attempt to differentiate the patients’ time outside of the hospital from their cancer treatment in the hospital, thus to challenge the way health care professionals label them “cancer patients” to redefine their medical identity for day to day day life outside the hospital. The avoidance of talking

about cancer with the health care providers' also stems from the ambivalence that some patients feel, since they *know* that they should be more open to doctors about their illness, but the large crowd of patients in the waiting room and the remote and patronizing attitude of doctors do not allow that.

Denying cancer is sometimes encouraged *even* by the health care providers. Before I started my research, the doctors and nurses at SSK and Güvercin hospitals told me not to use the word cancer while interviewing the patients, because they do not tell a few elderly patients that they have cancer<sup>32</sup>. Several doctors explained that if the patients are over 70 years old and do not have much formal education, they first give the diagnosis to those patients' children and consult them about telling it to the patient. In some cases, the children prefer to hide the diagnosis from their parent, telling them that they have a more minor health problem, such as weakness in the blood or a problem in the bones. However, Dr. Zehra, a female doctor at SSK, said that sometimes those patients understand that they have cancer during their treatment, especially when other patients tell them, but also hide it from their family in order not to upset them. She pointed out that sometimes she feels she is watching a comedy in the hospital when she observes the patients and their families knowing the diagnosis, but hiding it from each other.

Melahat, a breast cancer patient in her seventies, said that her doctor and her son told her that she had a tumor in her breast, but she did not know what "tumor" (*tümör*) was. Later on, when found out about what it meant, when she read a newspaper article, she had a "new wave of shock." However, she said that if her doctor said that she had

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<sup>32</sup> Although Güvercin hospital is a cancer hospital that only treats cancer patients, the doctors do not tell some of the patients that they have cancer, by explaining them that they would have a better treatment there. The SSK hospital's cancer section is called "The oncology and nuclear medicine," and since the word "oncology" is a scientific term, which is not used in daily life, many people do not associate it with cancer.

cancer directly, she would be more severely shocked, since by the time she read that article, she was already suspecting that she had a very bad illness, because of the treatment she was having. Although the health care providers often prefer to use the word *tümör* to *kitle* (hard entity in the body), arguing that it is more precise in medical terms, the patients, especially the ones at SSK, prefer *kitle* when they refer to the tumor in their body, since “it sounds more like everyday Turkish,” in Figen’s words. Three patients, who had their treatment at SSK, also argued that *tümör* is a cold word, which directly reminds them of cancer. The cultural construction of the words of *tümör* and *kitle* in popular and medical discourses is similar to the conceptions of *hastalık* and *rahatsızlık*, since in both cases patients and health care providers prefer to use either everyday words or medical terminology in describing cancer.

Even though I did not carry out formal interviews with people who were not aware that they had cancer, I encountered four or five such patients daily during my time at SSK and Güvercin hospitals. I also realized that the health care providers also avoid using the word cancer, and say the “disease” (*hastalık*) instead. They also use “becoming x” (*eks olmak*) instead of “dying,” and avoid using this medical term out loud<sup>33</sup>. The words cancer and death are taboo in these hospitals, and in most patient’s lives outside of the hospital context, as far as I know from the interviews I conducted in the patients’ houses and in the coffee houses, and the words themselves have a power of inducing fear and anxiety. Except for a few patients, coping with cancer often takes place through different degrees of denial, despite the efforts of cancer associations and Ministry of Health to make cancer more visible in the society. Even the health care providers further

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<sup>33</sup> This issue will be discussed further in Chapter 8, which is on facing death and dying.

this denial, by imposing the rule against the taboo words and hiding the diagnosis from some cancer patients.

**The Changes in the Social Interactions of Cancer Patients:** The second theme, which emerges in the illness narratives, is the changes in the social interactions of the patients that also include how the patients manage or cope with those changes. In accord with the importance of family in socialization in Turkey, I found that the patients I interviewed often consider their families to be the most important source of help and support for their efforts to cope with cancer. That is not always a smooth and unproblematic process, since social and economic problems, generational conflicts and patients' priorities in life influence the interactions between cancer patients and their family members.

My research indicates that especially the female patients have problematic interactions with their family members, and that has to do with the changes in the women's social and economic position in Turkey. Despite the Kemalist principles which encourage women to take part in the public sphere and work life, a more common view stresses that the women are primarily responsible for creating and maintaining families, unless there is an urgent economic need for them to work. This view, which is considered rather traditional or conservative now, confines the women in their homes and attributes to them the role of transmitting the proper cultural values to the next generations. However, the rapid globalization, urbanization and industrialization processes in Turkey since the 1980s have changed women's social and economic position considerably, together with their future plans, which do not necessarily fit traditional roles and norms. The feminist movement also has had an impact on many Turkish women in shaping their

priorities in life, which sometimes clashed with what their parents, siblings, husband and children expected from them. Some female cancer patients think that those conflicts can be harmful in psychological terms to the extent of causing cancer. Among the twenty-five women cancer patients I interviewed, eight of them directly associated their illness with the fact that they or their daughters did not lead a life in accord with the social norms. Those women talked about this in a “matter-of-fact” way rather than in a regretful tone, by emphasizing their individual difference and the economic and social advantages they won as a result of not living according to the norms and cultural expectations.

Sıdıka, a breast cancer patient and a housewife in her mid-sixties, explained that she and her husband had a divorce two years ago, after waiting for their children to grow up and become self-supporting. Her two brothers, a chief policeman and a businessman, opposed that divorce, arguing that it is ridiculous for a woman of her age, a mother of three children, to have a divorce, and that the divorce would ruin their professional prestige as well her husband’s, who was a judge. Sıdıka’s children were also uneasy about the divorce and told their mother to be patient with their father. Despite the protests, Sıdıka filed the divorce papers on the grounds that she and her husband fought constantly, and her husband beat her. The divorce process lasted six months, despite Sıdıka’s evidence of doctors’ reports of bruises and injuries.

Sıdıka explained that she felt like a total wreck after the divorce: “Since I went to the primary school just for three years and I have no special skills, there was no job that I could do, and financially I had to depend on my brothers and children, who were all against my divorce. I felt like an unwelcomed person...like a parasite. At that time, one morning I looked at my reflection in the mirror and felt horrible. I realized how much weight I gained in the last few years...I looked like an old, ugly and useless woman. I

cried for hours then.” After this incident, Sıdıka began to have a strict diet, as well as taking typing and English classes. She also did the decoration and renovation of the small apartment that she rented, with the help of her brothers. She said: “The diet consisted of having light snacks instead of a big dinner in the evening, and although it was not a radical diet it weakened me and led me to have cancer. I also became tired while taking all those classes and decorating my new house, and being tired made my cancer worse.” Sıdıka realized that she had a tiny lump on her breast, which also felt hard, when she was hanging her new curtains. She suspected breast cancer immediately, since she follows the news on it from the media closely and she went to see a doctor right afterwards.

Her cancer was detected at an early phase, so only a tumor was taken from her left breast instead of taking out her whole breast, and when I interviewed her she was having eight chemotherapy sessions that her doctor recommended. Although Sıdıka is conscious of the fact that her family considers being divorced and being on a diet at her age as “inappropriate,” she also proudly said that she wears much smaller sized-clothes now and she looks much better in general. She also added that she would start looking for a job for the first time in her life after her cancer therapy, which was covered by her policeman brother’s insurance, since she grew tired of being financially dependent on her family, especially when they do not approve of her new life style. Her policeman brother also mentioned that he found out about the Güvercin hospital for Sıdıka, and paid for the extra fees for the doctors there so that she could be treated there instead of at the SSK. I conducted a part of Sıdıka’s interview in her new house, and throughout the interview, his policeman brother who visited her, often came in and out of the living room. He interrupted her talk with his discouraging remarks, and after about an hour he brusquely cut the interview, telling his sister to have a rest. He also interrogated me about “my

agenda” and told me not to encourage Sıdıka to have any more strange ideas. However, despite the unresolved tension and economic problems between Sıdıka and her brothers and her illness, she seemed to be someone who is hopeful and who found a possible solution to her chronic problems in life.

If divorce at a later age is considered an inappropriate act, remarrying after a divorce at a later age or after the death of a husband is often more severely criticized by the other family members. Three female breast cancer patients over sixty talked about how their siblings and children turned their back on them when they remarried after the divorce or death of their husband. Since it is commonly believed that extreme stress is one of the most important causes of cancer, those women think that their conflict with their families is the primary cause of their cancer. Hamiyet, a fifty-five year old breast cancer patient whose breasts were removed at the SSK hospital said that five years after her husband died of heart failure she met her current husband, and they eventually decided to get married. Her current husband has a small vegetable garden, and he grew and sold vegetables. Hamiyet helps him in the garden, and she said that their economic situation is fine. However, her children, her sister and her husband’s children did not approve of their marriage and cut their ties with them. They argued that her current husband, who was in his early seventies, was much older than her, and even said that she married for the garden that she would inherit when her husband dies. Hamiyet became really upset because of those accusations, and she believed that she had cancer because of all that sorrow<sup>34</sup>. When her children and sister learned from other relatives that she had cancer they only called her to say they are sorry. She stayed at SSK hospital for a week during her chemotherapy sessions, since she has extra medication to “make her blood

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<sup>34</sup> The common association of sorrow and stress with cancer is discussed in Chapter 3.

thicker.” Hamiyet explained that she had just one neighbor to help her in the hospital: “She is the only one who makes soup for me and brings to the hospital. My husband is too old to come here, and he has his own health problems. But my biggest sorrow is that I do not see my children for the last five years and they do not care about their mother who has cancer.”

The people, who subscribe to the “traditional values” also expect young women to act according to the social norms and expectations, by being dutiful daughters and future mothers, and any deviation from those norms can be a major cause of sorrow and cancer for women. Ayla, a breast cancer patient and a housewife in her early fifties, explained that she had done her best to raise her three daughters, after her businessman husband died when her daughters were teenagers. She said she gave priority to her daughters’ education and wanted them become professionals, and eventually her oldest daughter became a bank manager in İzmit, a city that is three hours away from Istanbul. When Ayla’s second child became a high school teacher and was appointed to a public school in Ankara, seven hours away from İstanbul, Ayla said that she could not bear the pain to be away from her two children. She said: “My daughters and I, we survived all the hardships, including the death of my husband. We learned to keep on living by leaning on to each other... Since I do not have much education, sending all three of my daughters to university was my biggest dream, but how could I know that their education will take them so far away from me? One of them is appointed by her bank and the other one by the state, so how can I tell them to come back to İstanbul and find a new job, as if that is easy to be done?”

Ayla said that there are other women who had breast cancer in her family, so she knew that she is genetically prone to have cancer, but she also thinks that missing her

daughters activated this gene earlier. When I interviewed her, Ayla was having her second chemotherapy and her oldest daughter took a week off from her work to accompany her mother. Ayla's youngest daughter was still in high school, so Ayla thought she was too young to help her in the hospital. Ayla's oldest daughter, Perihan, who is 25 year old and single, said that she also does not want to be far away from her mother and would talk to the human resource department in the bank so that she can be appointed to İstanbul, even if that appointment can take months. Perihan was the "patients' model family member" for all the health care providers in the Güvercin hospital, doing all the paperwork for her mother easily and patiently, and constantly holding her mother's hand while she rests on the hospital bed. Although Ayla never openly blamed her daughters for going away to pursue their careers, she also mentioned that it is the children's duty to take care of their parents when the parents become old or sick.

Another duty that their family expects from daughters is to marry and have their own family eventually. Selma, a 34 years old uterine cancer patient, talked about how she was raised in a very poor family, with her eight siblings. Selma's parents migrated to İstanbul from a Central Anatolian village and they lived in a squatter area. Selma's parents both worked in a state factory, and, according to her, they had the mentality of a "state employee," never complaining about their wages or thinking of spending an extra effort to gain more money. Selma explained that there was a big rivalry among the siblings in sharing the scarce resources to the extent that there could be major arguments about how many olives or pieces of bread each sibling ate for the breakfast. That is why Selma remembered all that noise in her childhood house whenever she thought about having her own children, and prioritized being her own boss and having her own house

over getting married and having children in her life plans, despite the constant pressures from her family.

Selma is the only one who went to the high school among her siblings, and her classmates were usually from richer families than hers. Selma said that she envied her classmates' nice houses and vacations in holiday resorts, and that she wanted to have the same life standards. In her school they had computer classes, which was a novelty in the early 1990s, and which provided a crucial advantage for her in finding a well-paying job as an assistant manager in a private firm right after she graduated. Selma eventually realized her dreams of having her own house and her own textile company, which has regularly grown despite the economic crises, and she started to export the clothes, which her firm produced, to Europe and Russia. Selma said that the stress she had while working may be the cause of her cancer, and the way cancer has spread rapidly in her body is also related with her priorities in life. She said that although there were several guys around her who wanted to marry her, she has avoided marriage until she realized her dreams, and that is why she is still virgin.<sup>35</sup> Selma explained the connection between her virginity and cancer as such: "I do not regret about my childlessness, I have taken care of all my little siblings when I was growing up and now my siblings' children give me the opportunity to act as a mother...But I wish I was married and sexually active so that I would visit a gynecologist much sooner. I just had few flirts that is consisted of hand holding and kissing, so I never thought of visiting a gynecologist until my pain lasted longer than my period and became unbearable, and then it was too late since cancer was already spread all over my uterus."

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<sup>35</sup> In Turkey, many people consider women having sex before marriage as inappropriate, and back their argument with the traditional family values. Although this argument loses its influence in the middle and upper classes in the cities, it is still strong among people in the rural areas and first-generation migrants.

Selma said that her doctor at SSK hospital scolded her as well, by saying if she had come few years ago, she would just have a tiny tumor, which could be removed by an easy operation and she would not need all those chemotherapy and radiotherapy sessions. Selma was having her tenth and last chemotherapy when I met her, and in two weeks she would start her 6 radiotherapy sessions. She suffered from nausea, digestion problems and weight gain during her chemotherapy sessions, and said that she thought her doctor was absolutely right about early detection. She had her operation and the first few chemotherapy sessions at SSK hospital, where she heard about the Güvercin hospital when she was looking for a less crowded and more hygienic place with better health care providers, who would treat her with more care and attention. She was having the rest of chemotherapy sessions in Güvercin, and was planning to have radiotherapy sessions there as well, since she said that Güvercin is a much more “civilized” place than the SSK hospital. Selma was very happy to be able to afford the extra payment of “doctor’s service” in Güvercin. She also made a donation to the hospital to be able to have her chemotherapy sessions in a separate room. Selma noted that it is ironic that her work led her to be sick and also provided her money for a much better treatment than many Turkish cancer patients can afford. Her family “partly marginalized her since she is the only woman who did not get married among her siblings,” then supported her fully in emotional terms when she had cancer.

In their research about the social conceptions of breast cancer among different communities in Orange County, California; Chavez, Hubbel and Mishra (1999) also found out that the “Latinas” (Hispanic women who migrated from Latin American countries) view “bad” and “morally questionable” behaviors, such as taking birth control pills and having breast implants, as major risk factors for breast cancer. Despite the

social and cultural between those women and Turkish breast cancer patients, the changes in women's social position, which provide a challenge for the idealized, "traditional" gender conceptions, constitute a common point in both societies. Therefore, the common social concerns about those changes can be linked to the fear of having cancer in a similar way in both contexts.

Although the family members play a substantial role in shaping both the illness experiences and illness narratives, the women's new social position enables them to own their illness narratives. In his research on epilepsy in Turkey, Byron Good (1994) addresses the relationship between gender roles and illness narratives, by discussing about a young woman, Emine, whose "voice was appropriated by her family," mainly by her mother-in-law and sister-in-law, who talked about her epilepsy on her behalf. Good states: "Relations of power and gender are expressed not only in the structure of the story, in the point of view it assumes, but in the elementary framing of who is allowed to articulate the story, who has the authority to speak, to construct the illness which belongs not to an individual but to a family." Good conducted this research in 1988, and the close connection between the family dynamics and illness narratives that he pointed out is still valid in my research, which I conducted in 2003-2004. In most of the interviews that I made, the patients' family members, neighbors and friends often interrupted their talk, with their own versions of the patients' illness experience and comments. However, unlike the Byron Good's Emine example, most female cancer patients were able to tell their own illness narratives fully, despite the interruptions, which rather aimed at opening the patients' narrative further rather than the shutting them up. Except for Sıdıka, whose narrative was often interrupted by her brother, women seemed to challenge the submissive and dependent role that is traditionally attributed to them. Education and

financial freedom gave the women the courage and ability to do so, as we see in the case of Selma, and even facing cancer does not stop those women from living their own lives, having their own priorities and speaking for themselves.

In her research on cancer patients in Mexico, Linda Hunt (2000) points out that having cancer “requires renegotiating the privileges and obligations of the patient within familial and other social hierarchies,” especially in terms of gender role and identity. Cancer often affects the patients’ reproductive organs and ability, and the side-effects of its treatment, such as tiredness, nausea, digestion problems and pains, interrupt the patients’ daily activities to a large extent. Hunt argues that the patients can turn these problems and the liminal social position of having cancer into opportunities for “social empowerment” by using them as legitimate reasons for negotiating their gender roles. In that sense, the female Turkish cancer patients who related their illness to their or their daughters’ “unusual choices” that did not fit the social norms also renegotiate their or their daughters’ gender roles. They do so by combining them with the liminal social position of cancer patient and finding a new way to legitimize these choices through their illness, in the sense of “paying a price” for not fitting the norms. Their unusual choices in life set these patients apart from the rest of the women, who lead more “normal” lives in Hamiyet’s terms, and the fact that they have cancer underlines this difference further. Although Hamiyet said that she could be just OK knitting and watching television at home all alone like many friends of hers who had lost their husbands, she said she did much better in marrying again and sharing her life with another person, despite the conflict between her and her children. Similarly, Selma said that she never regretted that she does not have children, since her siblings have more than enough children to fulfill her instinct of mothering. The changes in the Turkish society gave those women the

opportunity to challenge the imposed social roles, and they managed to turn their marginal position in their families to a ground for further empowerment through their cancer experience and narratives.

Despite their stress on the importance of family support, the health care providers at SSK and Güvercin consider the well-educated and professional female patients to be the “good patients,” who can be role models for the other female patients. The nurses especially appreciate that those women’s files are neatly organized, without any paper or signature missing, and the doctors emphasize that “They speak the same language” with those patients. However, one female doctor in Güvercin and a male doctor at SSK said that they feel upset when those patients fail to have their own family and children, “because they focus on their career too much.”

**Patients and Their “Family” Members in the Hospital:** Besides the gender roles in the family and social position of women, the patients’ social interactions with their family members change considerably after their diagnosis and throughout their medical treatment. The families are actively involved in the patients’ illness experiences, and most patients are accompanied to hospital by at least one family member. The patients need their family members not only to deal with bureaucratic work, buy the medication and wait on line, but also to speak with doctors and nurses about the diagnosis and treatment plan. The patients prefer to share their illness experiences mostly with their close family members rather than with other people such as their friends, and colleagues. Altan said that his chemotherapy sessions affected his social life significantly, since he cannot visit his friends and sit on a couch for a long time. He said that when he felt pain, had nausea, or had to go to bathroom often, he felt embarrassed when his friends are

around, so he invited his friends to his house or went to their friends' house less frequently. Gülsüm mentioned that her friends insist that they have to go out and have fun together, so that she does not confine herself in her house and stay alone with her illness. She complied with those wishes only if her friends agree not to talk about cancer. Ayla said that if her friends display their sorrow because of her illness, she becomes uncomfortable, since she sees them mainly to get away from her illness in every possible way.

Except for the few patients who have no family support, there is a clear divide between the patients' family members and other people whom they are close to, in sharing their illness experiences and narratives, similar to the health care providers' prioritizing the patients' family over other people around the patient. Even if there are problems in the patient's family, as in the case of Hamiyet and Sıdıka, all the patients believe that the cancer experience should ideally be shared only within family members, who provide emotional and material support for the patients as much as they can. The patients feel the lack of their family members' support when other people help and support them. Hamiyet who was staying in the hospital ward with other breast cancer patients, explained: "Here we are six women who support each other fully in emotional terms, so much so that we became like a family. I have also got close to the other patients' family members who often visit this ward... Their children became like my own children. The hospital also allows some religious people who pray with us and distribute us rosaries that they blessed with their prayers. Of course, all these things are helpful for me, but I still miss my family members terribly, and feel their lack all the time. When I think that they never, not even once, came to the hospital, I feel like I am losing my mind."

Health care providers also prefer that the patients come to the hospital with their family members. Doctors sometimes have a separate session with the patients' close family members before talking about the diagnosis to the patient, in order to discuss what exactly to tell to the patient. When cancer treatments reduce or terminate the reproductive abilities of patients, doctors also have another session with the patients and their partners, if they are engaged or married, in order to discuss their plans to have children. Those sessions provide an opportunity for doctors and nurses to inquire about the private lives of the patients. For instance, when a doctor and a nurse, both female, in the Güvercin hospital were discussing with a young male lung cancer patient about the schedule of his radiotherapy, the nurse asked the young man:

“-There was a young woman who accompanied you in your first chemotherapy visits to this hospital. Is she your fiancée?

**The patient:** - (Pause) Err, yes, we were engaged, but we broke up a short time ago.

**The doctor:** -Oh, I am sorry; she seemed like a very nice girl. Anyway we were asking you about that, because of if you want to have children, this is the best time now, since in one month, you will be in the middle of the radiotherapy sessions and your sperm level will drop considerably and it will stay low for two or three months.”

Doctors and nurses are also more distant towards the patients who came with their neighbors and friends, such as Hamiyet, who married again after her husband's death, and Lerna, the Armenian breast cancer patient, who was coming to the hospital with her neighbor, because her husband was too old to come, her daughter was in school all day. When a nurse said that Lerna is “a little bit odd, since she comes to the hospital with just one neighbor,” I told her the reasons Lerna gave to me about that problem.

However, the nurse was still suspicious towards her and said: “you never know may be there is a problem in her family and she does not tell it to you.” The health care providers talked less with the people who accompany the patients, but who are not their family members, and keep their conversations limited to the topics of the patient’s illness and treatment.

Despite their stress on the family members’ support for the cancer patients, the doctors and nurses at SSK complain that the patients come with too many family members, and make the hospital even more crowded. They often refer to the large group of family members as tribes and clans, and complain that these people hinder their work, by asking unnecessary questions and creating all sorts of problems, such as forgetting the patient’s bed number and losing a curial document from the patient’s file. The patients and their family members at SSK fail to see themselves and the health care providers there as “one big family,” as the patients in Güvercin did, because of the crowd of patients and hierarchical and tense interactions between the patients and the health care providers.

Almost all the patients and people who accompany them complained about the harsh treatment of health care providers at SSK, but the tone of complaints about the doctors and nurses were differed. Doctors’ harsh treatments are somewhat tolerated because of the difficult job of taking care of the patients and dealing with matters of life and death. Füsün, a breast cancer patient in her forties, explained: “He is a *doctor*, he is not your equal, so you cannot possibly discuss anything with him, he tells you what to do, and you should do it, even if you do not like what you are told. Who else may know about what is going on in your body, other than the doctors?” However, the patients and the people who accompany them, respect nurses much less and direct their anger and

frustration towards them, since they also interact with nurses much more than they do with doctors. Esma, the sister of the uterine cancer patient Selma, argued that a nurse may decide to dislike a patient or a person who accompanies her because of a minor problem, such as a word her sister used or a look on her face. Then, for Esma, that nurse will do anything to hurt this patient, psychologically or physically, even to the extent of not including a drug that is against the nausea inside the chemotherapy medicine. Fatma, who is the sister of Feride, a breast cancer patient in her twenties, said that the nurses often have bad days and project their mood to whomever they find in the hospital. For Fatma, since the nurses think that it is not very appropriate to hurt the sick people's feelings, they often target the people who accompany the patients for "a good fight" that would wash away all their stress. She half-jokingly argued that there must be a special test at SSK, which admits all the nurses with severe psychological problems to its oncology clinic, since she came here at least ten times, and she never encountered one single nurse who is normal.

Although the doctors and nurses at SSK complain about the number of family members who accompany the patients, those people are equally, if not more involved with the hospital bureaucracy, and interact with the health care providers, sometimes even more often than the patients. Fatma said that her sister Feride came with three sisters, including Fatma, and her cousin, and that even if one of them would not come to the hospital, it would be very hard to deal with bureaucratic matters. She explained: "We all came at eight in the morning and until 12.30, when Feride was given a bed for her blood medicines<sup>36</sup>, all four of us were busy one way or another. One of us stayed with Feride to

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<sup>36</sup> Many cancer patients at SSK get certain medications to "Thicken their blood," so that their blood can have the necessary number of red blood cells, before their chemotherapy and radiotherapy, both of which

provide anything she needs, the other waited in line to get her medications, I waited in front of the chief doctor's room to get his signature for Feride's file, and our cousin tried to reach Feride's doctor to learn when she will examine her. So, all of us were really busy and I cannot imagine how hard it would be to do all these things if we were just one or two people with Feride." Most patients and their family members at SSK agreed with this view, and also emphasized how much they pity the patients who have no one to accompany them.

During my fieldwork I observed that the cancer patients and people who accompany them often act as a team, which is coordinated by the patients, who start to build their team when they learn about the diagnosis. Cancer patients decide which family members to tell about their illness and which of them to ask for help in the hospital. There were five cases where the children of cancer patients were too busy with their work or classes, so that the patients delayed telling them that they had cancer. Yılmaz explained that his daughter was in the last year of high school, and she was working hard for the university entrance exam when he was diagnosed so he and his wife did not tell her about his illness until she took the exam. After her exam, Yılmaz just told her that he has a bad illness, which requires a long-term treatment, without saying that it was cancer, in order not to upset her in her first year of university. Similarly, there were four cases, where cancer patients did not tell their parents or spouses, because they are old and have their own health problems.

The patients' decisions on whom, when and how to tell about their illness require them having certain strategies, which also empower them by providing a sense of control

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reduce those cells significantly. This process requires that the patients lay in bed in the hospital for 6 to 24 hours.

over the course of their illness and treatment. Selma explained that when she learned that she had cancer, her first thought was whom to tell this news in her family: “I did not want my parents know that for a while, since they will get really upset and they will cry for days, which would demoralize me to a great extent...I talked about it to my siblings, since I knew that they could be almost as strong as I was in facing the cancer, and really helped me in my battle against it, instead of just whining.” Yılmaz, first told the diagnosis to his wife, who was with him in the hospital that day, because he knew that she would have a similar reaction: “My wife and I, we decided that we should always be cold-blooded during the treatment, whatever happens to me. I also thought about including a few other people in my hospital visits, such as my brother, who has the same mentality with us.” Although the patients and their family members act as a team in and outside of the hospital during their cancer treatment, which does not necessarily mean that the patients fully share the problems that the cancer and cancer treatment bring to their lives. I will discuss that issue in Chapters 6 and 7, which are about the bodily changes that the patients go through and how they cope with them.

## Chapter 5

### **Urban/Rural Lifestyles, Modernity and Global/National Affairs: The Major Themes in the Treatment Narratives**

A large part of the cancer patients' illness narratives consisted of their treatment experiences, which can often be considered to be the core of these narratives. In their research on Israeli breast cancer patients, Susan Sered and Ephraim Tabory (1999) suggest that the patients offer them "treatment narratives," which are the "tales of failure and success in negotiating the medical system." The authors argue that during long-term medical treatment "The medical system becomes the cultural context in which the patients' understanding of reality, sense of self, and key interpersonal relationships are formulated and played out." This argument is also valid for the Turkish cancer patients' experiences during their treatment, and the patients have several criteria for defining their successes and failures in negotiating the medical system. The medicalization of Turkish cancer patients' life goes beyond their experiences in the medical institutions: It changes their everyday lives, social identity and elicits their opinions on different political, economic, social and medical problems in Turkey.

The cancer patients' description and evaluation of their treatment constitute a major part in the interviews at Güvercin and SSK hospitals, and also in the illness narratives written by the public figures<sup>37</sup>. In this chapter, I will discuss three main themes that are prevalent in the oral and written cancer narratives, and relate them to the

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<sup>37</sup> I discussed these books also in the Chapter 3, which is on the social conception of major diseases and cancer in Turkey.

arguments mentioned above: The attitudes towards urban and rural life; views on modernity, science religion and education; and discussion of global and Turkish politics. These themes are also discussed extensively by politicians, scholars and journalists, with respect to the historical transformation and social stratification in Turkish society. These broadly defined themes will enable me to analyze how the cancer patients conceptualize these issues through their experiences in the medical institutions and health realm in general. The themes are interrelated and they often overlap both in terms of the categorizations they involve and patients' value judgments. They allow the patients to give meaning to their treatment and to connect this personal meaning to more general public debates. How the patients view and benefit from the alternative or complementary medical methods, and how the patients categorize good and bad patients and health care providers are also connected with these themes in different ways. The investigation of main themes in the treatment narratives indicates how the social and political problems in Turkish modernization are reflected and reproduced in medicine.

**I) The Cancer Patients' Attitudes towards Rural/Urban Dichotomy:** Although I did not ask about the rural and urban lifestyles and their association with cancer in particular, eleven patients raised this topic in different ways. Eight of them are the first or second generation of migrants from rural areas to the cities, and they still have close ties with that environment. These eleven patients associated "the village" with a healthy life, and warm and honest people who help and support each other fully in health and sickness. This idealized image of "traditional village life," in Selma's words is contrasted with the difficult city life, urban pollution and cold and selfish people who belittle the migrants. In the earlier decades of the Republic, Atatürk also idealized the traditional village life,

and associated its “purity” with the essence of being Turkish, and by stating “the villager is the master of the nation.” The early Turkish nationalist politicians and intellectuals also adopted these views, and looked for possible ways to combine the purity and unpolutedness of village life with the cultural and scientific benefits of modern Western civilization, by excluding its moral decadence and individualism. That discourse, which idealizes the rural people and life, still exists in today’s textbooks and schools in Turkey, and the cancer patients also used this discourse in comparing urban and rural lifestyles and people.

Six cancer patients, four of whom had most of their treatment at SSK, associated their cancer with their migration to the city and problems in adapting to the city life in social and economic terms. The cancer patients who talked about the “healthy village life,” also emphasized the difficulties that they had in adapting to city life. The medical institutions that they have to visit regularly also created a new set of challenges for them to overcome, in terms of the bureaucratic system and interactions with health care providers. Abdullah, a lung cancer patient in his forties, migrated from a village near Sivas in the Central Anatolia more than twenty years ago, and considers himself well-integrated to the city life in economic terms, since his career evolved from washing dishes in a restaurant to becoming a restaurant owner. However, he said that despite his economic success, many people in the city, especially the SSK hospital’s health care providers, would always treat him as “an ignorant villager.” As I have also discussed in Chapter 1, Abdullah said that “there were all sorts of harsh treatments, only excluding the actual beating” by health care providers towards him and the “people like him.” He argued that the SSK health care providers categorized him too easily by judging him from his Central Anatolian dialect and “villager’s clothes” and discriminated against him: “The

doctors and nurses at SSK just look at me and decide what kind of a person I am, and they behave accordingly... Even if they do not say anything, I understand everything from the way they look at me coldly or their harsh behaviors towards me. This is just so wrong and it is against the principle of equality of all citizens! ... I could, of course, spend an effort to talk and dress like most men in Istanbul. May be, even my own children would prefer that. You know, my daughter actually asked me to wear jeans, white t-shirt and a black jacket for her high school's graduation ceremony two years ago (What did you do, then?) Of course, I just laughed so hard. I can never even picture myself in jeans, and so I have never worn them!! (How about the changing your dialect, what does your family think about it?) There is simply no way for me to talk like the people in the public television. For instance, my daughter who is raised here, talks like those people, and I am proud of it, but it would be so pretentious for me to speak like that, as a man who likes to be natural all the time... If the staff at SSK behaves badly towards me just because I am not pretentious, it is their fault! What can I do?"

Abdullah viewed the bad attitude by the medical staff at SSK as a typical example of the problems of living in the city as "a villager," although he believed that "having all that education" the doctors should behave in a better way. During the interview, he kept emphasizing how he was proud of his rural roots and that he would not do anything to deny these roots. He also supported the recent migrants and the university students who come from Anatolia, and this gives a spiritual satisfaction to him: "Although it has been years, I still remember how bad and lonely I felt when I moved to İstanbul, everyday was bringing new difficulties for me. Years later, when I opened my restaurant, I did not want the other people suffered the way I did, so I hired mostly the recent migrants and university students from Anatolia. I gave them pretty good salaries too, and I was very

flexible with their hours. You cannot believe how many people worked in my restaurant throughout their university education and became lawyers, doctors and businessmen. I consider this as the best, most spiritually satisfying thing that I have done in my life. All these people who found jobs thanks to me see me as their father and I see them as my sons, they keep visiting me to kiss my hand and ask me how I am doing. For instance, one of them became a doctor in a medical lab, and that is why I never have any difficulties in having my medical tests. Over there, he treats me like kings in contrast to the SSK, and even if he does not want me to pay anything for the tests, I pay secretly to the secretaries.”

According to Abdullah, his support of the newcomers to İstanbul is also a typical way that the villagers act: “In the villages, we do not have all the luxury you have in the cities, sometimes when it snows, the roads to the cities are closed and we cannot have anything from there. Maybe because of these difficulties or because of the villagers are not as degenerated as the city people, we help each other all the time in order to be able to survive. Here, when you have cancer even the people you see as friends or good neighbors do not care about it. They do not ask you how you are or do not even cook a soup and bring it to you. They simply stay away from you, when you have a problem in the city, whereas in the village people do their best to help you.” Abdullah spent one month in the summer in between his two sets of chemotherapy treatments and he reluctantly returned to İstanbul afterwards: “In the village, everything was better, the food was tastier, the water was cleaner. The water was so clean that you could drink a handful of water from any creek. The air was also so clean that when you took a breath you could almost feel your lungs becoming bigger and cleaner, but more important than all these was the people’s warmth. Everybody in the village visited our family house and asked

what they can do for my illness. They brought all sorts of home remedies, roots, herbs, *muskas*, you name it... I really wished to stay there longer, but I had to go back for my chemotherapies and my restaurant... Sometimes I think that I would not have cancer if I did not move to the city. I live a better life than the villagers in a material sense, but it does not necessarily bring happiness.”

The idealized description of the village life as being healthy is also related with the common association of cancer with the rapid urbanization and industrialization in the society since the 1980s, as I discussed in Chapter 3. Despite the fact that there are “cancer villages” (*kanser köyleri*), in Central Anatolia, Thrace and the Eastern Black Sea Coast<sup>38</sup>, the cancer patients more readily associate cancer with the cities and urban pollution because of the recent urbanization and industrialization processes. Therefore, cancer allows those patients to speak the ills of Turkish modernization in the sense that the urbanization and industrialization processes, which are two important aspects of the Turkish modernization, have caused an unhealthy life for many people. Yılmaz, a lung cancer patient and an active member of a workers’ union, talked about how these policies increased the contrast between urban and village life in terms of health standards: “When they think about the city life, many people will also think about pollution immediately. It is because the politicians encouraged thousands of people to move and settle down in the city since the 1980s, and brought the “car culture” in the 1990s. Even the poor people bought a car with the bank credits. Now we have all those big highways, even in the middle of the city, but we also know this had grim consequences for the people’s health.

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<sup>38</sup> The term cancer village is a popular term since the mid-1980s that is used to describe the villages, where the cancer rates and mortality due to cancer are high. Several scientist conduct research to find the reason of high cancer incidence and mortality in these villages. The common popular and medical explanations for this problem focus the asbestos, which is used in the rocks, which are used to build houses in Nevşehir, Central Anatolia, and “The Chernobyl effect” in the villages of Thrace and eastern Black Sea Coast” so far.

You probably remember that the primary and high schools were closed for days in the 1980s and 1990s because of the fog in Ankara, right? What kind of fog was that, which alarmed all the politicians so much? Now you take a breath in the city and you don't know what kind of chemical entities you take into your lungs, it may be totally polluted... Ironically, I understand the extent of air pollution, when I go back to my parents' village (Where is that village?) It is on the hills of Samsun, so you have both the mountains and Black Sea air over there, and because of really clean air I feel a little dizzy for the first few days when I am there. As a city person, it takes me a while to get used to that pure, clean air (He laughs).”

The idealized “healthier village life” theme also came up in a similar way in the interviews of five other people, one of which is Figen, who is a primary school teacher and a breast cancer patient in her thirties. Although she was born and raised in İstanbul, her father is from a village nearby Trabzon, in the Eastern Black Sea coast, and she regularly visited that village in the holidays: “The first couple of years when I was teaching, I had to participate to various seminars in the summer and I was also busy in moving to my own place for the first time. That is why I could not go to my father's village for 3-4 years, but when I went there after all that time, people greeted me so warmly that I wished I were not away from there for a such a long time...There is something so pure in the village life and people that a few hours after I go there, I begin to feel much better both psychologically and physically. I leave the big, polluted city behind me, it feels like it is thousand kilometers away.” Figen's cancer was diagnosed three months ago, and she was having her last chemotherapies, after her surgical operation where her left breast was removed. When I interviewed her in March, she was planning to take a sick leave after her treatment and stay in her father's village for 6-7

months, as a “long and relaxing summer holiday,” in order to overcome the physical and psychological effects of cancer treatment: “I also feel like I will be more comfortable about my bald head and the lack of my breast over there. It seems to me that everyone is giving me weird looks in the streets of İstanbul, but no one dares to ask any question about my baldness or the lack of my breast, even if they notice it. I just hate that awkward silence and superficial politeness. In contrast, the people from my father’s village came to visit us in İstanbul, and they all asked about the operation and treatment, some of them even wanted to see the scar on my chest, and an old woman thought that it looks like a blossoming flower! (She laughs)... I felt more comfortable when they were around me, and I will go to the village because I will be surrounded by these honest people there.”

The same theme about idealizing the healthiness of the village life also appears in the cancer narrative of Sibel Kalaycı (2004), who is a breast cancer patient and a journalist in her thirties, and who spent her childhood in her parents’ village in Trabzon. Kalaycı’s initial reaction towards her diagnosis with cancer was having an urge to “go back to her village” in Trabzon, even though she can have a better treatment in İstanbul: “My heart and soul want to go back to Trabzon. I do not care that we have better treatment options here...I feel like everything will change radically and the word cancer will be forgotten if I go back to Trabzon. It seems like I behave like an ostrich again. Going back to Trabzon is like going back to my mother’s womb. My childhood in Trabzon was so happy and safe...” Since Kalaycı wrote her book after her treatment was completed and she is cancer-free, she can take some distance from her idealism and nostalgia, as we see in her quote, which still describes her emotionally powerful urge to go back to the village, which she associates with her happy and safe childhood.

## **Unequal Health Care in Urban and Rural Areas and Changing Conceptions**

**of Health and Illness after the Migration to the City:** Despite their idealized description of the village life and nostalgia for “going back to the village,” the eleven cancer patients were concerned about the lack of proper medical services in the rural areas, unlike Sibel Kalaycı. For instance, Altan, the retired architect, planned to move to a small village in the Aegean coast, in order to spend his days fishing, swimming and sailing, but he had to cancel that plan because of his colon cancer treatment. He argued that the health care inequality in geographic terms in Turkey affects the cancer patients the most: “Even if all of the doctors who see me will say that I am fully recovered, I will wait a year or so to move out of İstanbul to that small village nearby Foça. During my treatment, I realized that cancer is such an unpredictable disease, for instance the doctors say that you will be fine after a set of eight radiotherapy sessions, then at the end of one set, they decide to prescribe one more set of radiotherapies, and it keeps going on and on like this. You also never know whether this trouble will occur again in a different part of your body. That is why I also believe all cancer patients in Turkey must find a way to live in the big cities, Ankara, İstanbul, İzmir or nearby, because the best medical facilities are there... Because of my father’s job as an officer and my projects of building house complexes, dams and factories, I saw every single region of Turkey, and I cannot tell you how backwards they are in terms of medical facilities. Forget about cancer, even if you have a slight complication in giving birth, you and your baby are either dead in a so-called, pathetic health clinic, which does not have the basic medication or a specialist... You have to travel for hours to a city if you have to visit a proper hospital. So just think, as a well-treated cancer patient, how would you feel if you notice the same symptoms a few months later and the hospital, which can treat you, is kilometers away? .”

The descriptions of villages without proper medical facilities and villagers' efforts to travel to the cities for these facilities are also a part of the common discourse on the Ottoman negligence of rural areas and the modern Turkish Republic's aim to overcome the social and economic problems that were caused by that negligence (Dole, 2005). As I discussed in Chapter 3, the health projects, which were started with that aim could only be partially successful and the accounts of "challenges that the villagers experienced in receiving health care" in Dole's terms, still prevail. Christopher Dole (2005) describes the early efforts in the modern Turkish Republic to bring science and technology to the "remotest corners of the country" both in terms of building medical institutions and inculcating the discourse on the superiority of modern medicine over other health views and practices. He argues that the accounts on the challenges that the villagers experienced in receiving health care also indicate their "remarkable desire to be treated by doctors" and the effectiveness of inculcation of the "superiority of modern medicine" view. The view of modern medicine as superior is also related to the Turkish conceptions of science and medicine as highly prestigious and respectable guides in leading the nation towards the modernity, as discussed in Chapter 3. However, besides this idealistic image of modern science and medicine, the cancer patients' view of modern medicine is also influenced by the "endless" medical tests that they have to go through and a treatment that affects their everyday life, social interactions, and bodily functions. Modern science and medicine also directly remind them of the bureaucratic, economic and social problems which they often experience during their cancer treatment. Therefore, Turkish cancer patients have a dualistic discourse on modern science and medicine, which is informed by both its rather abstract and idealized conception associated with modernity, and their often problematic personal experiences in the medical institutions.

The cancer patients' dualistic discourse on modern science and medicine lead them to evaluate living in İstanbul, where they have easy access to modern medical knowledge and institutions and where their everyday life is fully medicalized, as not necessarily beneficial in every way. That is also why some cancer patients have still nostalgia for or a dream of living an idealized and healthy life in a village, despite the lack of proper modern medical facilities there.

The differences between urban and rural areas in terms of the level of medicalization in Turkey also lead the cancer patients to change their conception of diseases after they migrate to the city. According to the cancer patients' accounts of health and illness issues in "their village," disease is a part of the reality of everyday life, which people accept and live with, rather than thinking that it should be eradicated at all cost. Talking about her childhood in a village near Tokat, Hamiyet, a breast cancer patient in her fifties, pointed to the conception of health and illness in her village, which was not shaped by the medical discourse and institutions and which may be beneficial in certain cases: "When we lived in the village, we did not know the name of the disease we had. We used to work day and night, trying to raise crops in an arid mountainous land. Then possibly out of tiredness and old age, we would just get sick, become bedridden and may die at the end, if the home remedies did not work. We would just say the time of death, which was inscribed in our faith before we were born, came. The nearest health clinic was three hours away and we would go there rarely, may be only in the case of broken bones or difficult births. We did not know what cancer was and how it was treated. I heard about the names of many major diseases for the first time when I migrated to İstanbul. (Do you have any family members with cancer?) May be some deaths in my family were due to cancer, I have no idea. Actually, I believe that sometimes it is better

not to know anything about your disease and not to have this torture-like treatment. It seems to me that it is more natural and in peace with the life itself, that way. You should not fight with your destiny so aggressively.”

These views are similar to the Inuit’s conception of health risk, as described by Patricia Kaufert and John O’Neill (1993), in their article on different discourses of risk in childbirth. Accordingly, both the Inuit people and Anatolian villagers view the health risks as a natural result of living in harsh physical environment, where people’s health depended on their own competence and self-reliance. Although Northern Canada and rural Turkey are highly different in terms of geographical and social conditions, they are similar in the sense that the people have their own cultural conceptions of health, health risk and illness, which are more in accord with how they live and view life and death, rather than the discourse that is inculcated by the political and medical institutions.

**City People, Good Migrants and the “Other” Migrants:** The patients who doubted that the medical treatment in the city is more efficient than the treatment with home remedies in the village are treated at SSK hospital, which is much more crowded and has more institutional and bureaucratic problems than Güvercin hospital. A young male doctor in the Güvercin hospital explained the difference in the quality of the treatment in the two hospitals, and how this difference is related with the rural background of the patients: “Of course, we also have patients who are first generation migrants from rural areas, but compared to the ones at SSK they are more aware of the advantages of the city, they are more integrated in economic and social terms. In some cases they came to the city only five or six years ago, and I am surprised to see how much they learned here and their condition became better in such a short period...It is like a

vicious circle, the people who are aware of the educational and medical institutions of the city and how these institutions can improve their quality of life do their best to benefit from these institutions... They give birth to just one or two children and do their best to send them to the schools. They try to be friends with the people who know the city better than they do... I believe through such friends, they hear about the Güvercin hospital, which is cheaper than any other private hospital, but which is as good as those hospitals in terms of medical services and patients' comfort, and these patients end up having a good cancer treatment... The more good experiences they have in the modern medical institutions in the city, the better they like living here and adapting to its life style. In contrast, the more people live like they live in their villages in İstanbul, they are treated as 'misplaced villagers' and they become reactionary or nostalgic." That doctor differentiated the good migrant patient from the bad one, with a modernist approach, by emphasizing the migrants' adaptation skills and integration to the modern city life rather than the migrants' own health practices, "which should be left back where they come from."

According to a male doctor at SSK, the "good migrants" are as easy to deal with as the "city people," since they eventually become like city people: "You know in İstanbul, we are all from somewhere and everybody in the city has a couple of relatives with rural origins, if we look at our ancestors... Some of my classmates in the medical school had parents who migrated from the poorest parts of the Southeast Anatolia and who worked so hard that they could afford their children's medical education. Therefore, with these thoughts in mind, I try my best to tolerate the recently migrated patients and treat them well. I speak slow and out loud with them to make myself clear." However, as I discussed in Chapter 1, most health care providers and patients identify the recent

migrants who did not adapt to the city by their dialect and clothes, and they may not be as “tolerant” as that SSK doctor towards those patients, whom they held responsible for most of the problems at SSK. Seven cancer patients said that they avoid the SSK hospital as much as possible because of the migrants who “suffer so out loud that they scare away the other patients,” in Selma’s terms. Selma argued that one of the main ways to adapt to the city life is to learn how to behave in the hospital: “Although my parents migrated to İstanbul decades ago, they still have the village mentality in many ways. (What does that mentality include, can you give examples?) For instance, they think women should marry young and have several children, and they could not even imagine that a woman could be an entrepreneur, until I opened my textile firm (She laughs). However, they also learned about the importance of education here and they are happy to live in a city with all sorts of medical facilities. Whereas many people at SSK seem to suffer just because they have to visit there regularly for their treatment. They live like they lived back in their village but they actually live in the middle of the city now. When they cannot behave as if they are in their village and have to obey certain rules, like not sitting on the floors or dumping their garbage in the waiting room, in the hospital, they become upset. For me, they are very hard to be around with their constant crying and whining about their disease and the problems that they have about the medical treatment or hospital bureaucracy... They make me feel depressed and more pessimistic about the people who do not even appreciate the modern medical methods that are healing them. How can our nation become truly modernized when there are hundreds of people like that? Let alone, we still have hopeless dreams about becoming a European Union member! I always think about what would happen if someone from these E.U. committees ever visits the SSK one day. Probably he would be utterly terrified and would do his best to not take us in their union

(She laughs)...I get upset in thinking all these things and in order not to tackle these problems in the middle of my cancer treatment, I began to avoid the SSK as much as possible. I go to the Güvercin hospital for my chemotherapy and I buy the drugs from the pharmacies nearby, and when I have to get the signatures for my insurance from the SSK, my sisters go there and deal with it.”

The patients’ urban or rural background and their adaptation to the modern city life and its “advantages” such as having a better access to medical institutions are important criteria for the categorization of the patients, as well as the patients’ evaluation of their cancer treatment. Having a rural background leads the patients either to embrace their “villager” identity and criticize certain aspects of the modern medical system through that identity, as in the cases of Hamiyet and Abdullah; or exclude that aspect of their identity, as Selma did, by fully adapting to the city life, as well as criticizing the people who still live like a villager in the city. As for the patients who considered themselves as having an urban background, such as Altan, the village is a healthy place in terms of its clean environment and fresh food, but people can only live there as long as they are healthy, because of the lack of proper medical services. Moreover, most of these people keep their interactions with “uneducated villagers” in minimum in general and in the oncology clinics, “since they do not have much in common” in Gülsüm’s terms or “their villager habits bother them” in Selma’s terms. The characteristics which differentiated the “villagers” from the city people are the dress codes, thick dialect, and publicly “whining” about health problems as described by Abdullah (who see himself in the first category), Gülsüm, Altan, Selma and Filiz. However, Altan and Selma also suggest that the “villagers” or “bad migrants” can be integrated to the city life eventually in social and cultural terms, depending on their professional and social interactions in the

city and within the typical urban institutions such as schools and hospitals. Therefore, despite the idealistic description of the village life and dualistic discourse on the benefits of modern science and medicine, many health care providers and cancer patients evaluate the patients' rural and urban background and how it affects their identity and life style, as crucial in shaping their interactions with those patients. These interactions often take the form of mutual alienation, discrimination and double standards as the above examples indicate. The rural and urban background of the patients also leads the health care providers and other patients to have various assumptions on those patients' attitude towards modernity, science, education and religion, which may not necessarily be valid. I will discuss these issues in the next section, which is the second major theme of treatment narratives.

## **II) Different Conceptions of Modernity, Science, Religion and Education:**

Fourteen cancer patients included their views on science, religion and education in their illness and treatment narrative. The patients relate these views to their conception of Turkish modernity, and evaluate different popular views on modernity in accord with what they experience in the medical institutions. As I discussed in Chapter 1, since the mid-1980s, the people with religious or conservative views severely criticized the dominant conceptions of Turkish modernity and modernization project and tried to replace it with alternative conceptions of modernity, which is less elitist and more inclusive of people with different views and life-styles. The dominant conceptions of Turkish modernity date back to the early 19<sup>th</sup> century, and they include the massive projects of introducing Western life style, ideas and institutions to the country in order to reach to the same level of civilization. These conceptions differ from one another in

terms of which Western institution or idea should be given priority for its introduction to Turkey, and how to combine these Western elements, with the “essential” Turkish culture. These projects also include a large-scale education of the masses in order to transform them into modern citizens of the new republic. However, many people criticized these conceptions, because of their top-down approach and daring to change how people lived and thought for centuries in a radical way. These criticisms constituted the base of identity politics between Kemalists and Islamists<sup>39</sup> and main differentiation in the attitudes towards Turkish modernity, which became influential in everyday life and the main institutions of the modern state since the 1980s. Medical institutions and health care providers, having a close historical association with the Turkish modernity, as I discussed in the first chapter, and played an important role in reproducing or re-shaping the cancer patients’ views on modernity, science, religion and education.

The fourteen cancer patients explained how they view science, religion and education, and Turkish modernity in talking about different reasons for having cancer, the attitude of health care providers and other patients, and alternative or complementary medical views and practices. Similar to the dualistic discourse I discussed above, although some of these patients criticize several aspects of Turkish modernity and the modernist conception of science, medicine and religion, they still accept in principle modern medicine and medical institutions as the ultimate resorts for the treatment of cancer or any other major disease. These patients can be divided into two main groups, in terms of the way they speak about these issues, in accord with the conflict of two social identities mentioned above: The first group, which consisted of eight patients, adopted a

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<sup>39</sup> The word Islamist is mostly attributed to the people who live in accord with the Islamic rules by the secular Kemalist people, and the people who are called Islamist prefer to describe themselves as religious or conservative.

typical modernist view, and suggested that the problems in the application and institutionalization of modern medicine can be overcome in time by educating people on how and when they can benefit from modern medical institutions. These patients also argued that religious views and practices should be confined to the personal or familial space as much as possible, since public space should be completely secular. On the other hand the second group of patients argued for the necessity of co-existence of religious and secular views and practices both in the public and private spaces. They criticized the current Turkish modernity as excluding and discriminating against the people who think and live outside its norms and values and being intolerant of the religious practices and organizations that shaped Turkish people's lives "for centuries" in Feriha's words.

#### **The Modernist Patients' and Their Views on Education, Science and Religion:**

The first group of patients was mostly from an urban background, and seven of the eight were having their treatment in the Güvercin hospital. Altan was the most typical in terms of representing the issues that they advocated, and he was highly vocal about the association between the problems in the Turkish medical realm and difficulties in the Turkish modernization process. He argued that the success of the Ottoman Empire was due to the Ottoman sultans' ability to combine the rich cultural, economic and scientific realms of the country's minorities, such as Arabs, Greeks and Armenians and successfully rule all these ethnic groups who co-existed peacefully for centuries. According to Altan, it was Atatürk who started the real modernization process in Turkey, since he realized that a full-scale introduction of the European mentality and institutions was necessary for the new Turkish Republic. Atatürk's modernization project differentiated Turkey from the other "third World" countries, especially from the Arabic ones, which did not have

such a leader with a vision. Therefore, he prioritized a large-scale educational campaign, which targeted the whole society. However, Altan also believed that Atatürk's project of educating the people with modern, Western ideas and values was left incomplete, since the leaders who followed him lacked his vision and efficiency: "That is why his battle with the people who abuse religion and with the superstitious beliefs and practices remained incomplete... The religious people became uncomfortable in a secular system, since Islam could not manage to renew itself since the 18<sup>th</sup> century, and the great scientists who were well known in the whole world, such as Avicenna, never came out in the Islamic world after the Middle Ages. The today's Islamists cannot understand that Europe has won the race of civilization and they resisted modern sciences and medicine. That is why I still see people who think silly *muskas* and meaningless prayers of greedy *hocas* can cure their cancer even though they have the medical treatment with the most recent medical technology and knowledge. I think this is pure ignorance and we must have a second Atatürk to educate all these people!"

Altan also explained that the interruption of Atatürk's educational campaign after his death led Turkish people to be alienated from their moral values and adopt the "bad aspects" of the Western world, such as "a greedy version of capitalism" in the 1980s, where people are mainly concerned about their economic interests. Altan noticed that problem in the Güvercin hospital when he saw several cancer patients who demanded that the state should cover all the expenses in their cancer treatment, including the payment of relatively cheap drugs and needles, even if they had the economic means for them. He also blamed the doctors who prioritized their economic interests in their professional practice to the extent of behaving immorally, such as the doctors who asked for unnecessary tests from the patients and who were involved in organ trafficking. Altan

argued that if the leaders who came to power after Atatürk continued his reforms in educational and medical realms, then the country would not have such problems. In that case, the patients would fully believe and respect their doctors, whose only priority would be curing their patients at all cost and serving for the scientific and medical development of their nation.

Atatürk and his reforms in the health and education came up in the interviews of two other cancer patients, Selma and Yılmaz, who are also among the first group of patients in terms of their attitude towards modernity, science, religion and education. However, Selma and Yılmaz interpreted these reforms in a different way. Yılmaz contended that the success of Atatürk's reforms in health and education had more to do with Atatürk's egalitarian vision than his "merely copying what is in the West in Turkey": "I get furious when all the elite and rich people declare that they are Kemalist, without really understanding what he wanted to do for his country. Atatürk wanted to establish modern schools and hospitals not only for the rich people in the city but also for the poor people in the rural areas... He wanted to bring an equalitarian system in the medical and educational realms so that the poor villagers have the same opportunities with the urban elite... However, because of his early death, his projects remained incomplete, and his successors preferred to continue the elitist system of the Ottoman Empire... The rich families of the Ottoman Empire are still very well-off, and the poor are still really poor, as well as being extremely religious, superstitious and ignorant. Therefore, it is hard to call the Kemalist reforms a "revolution," since they were left incomplete, because of the collaboration between elites and politicians after Atatürk. Therefore, you still see poverty, abuse of religion and ignorance all over the country, including the oncology clinics of course (Can you give examples on how you see those in the clinics?) For instance, all

those people at SSK, they benefit from the modern medicine, but since they do not trust it fully they also go to the charlatans who call themselves religious leaders to seek a possible cure for their cancer. If modern medicine cannot cure cancer with all that knowledge and technology, how can an old guy, who does not do much but babbling prayers, cure it? (He laughs).”

As I discussed in the previous section, Selma also believed that Atatürk’s reforms are left incomplete since there are still social tensions and inequalities between the conservative people of mostly rural origins and open-minded people who can adapt well to city life. For her, this is the most chronic problem in Turkey for centuries, which “even Atatürk could not solve.” Selma thought that most problems in the public hospitals, including SSK, stemmed from these inequalities and tensions, therefore a health reform by itself, without “reforming the whole social structure” would be ineffective. It is interesting that these patients often praise Atatürk and his reforms in talking about modernity, science religion and education, but they focus on different aspects of these reforms and have different interpretation of what their aims were for the society and medicine.

Being the key figure of Turkish modernity, Atatürk is also known for his promotion of Turkish medicine and his refusal to be treated by foreign doctors for his lethal chyrosis. In his book on his cancer experience, Kazım Kanat (2003), a well-known sports commentator and a liver cancer patient, praises this attitude of Atatürk. He also emphasized how well he was taken care of by the Turkish doctors and nurses in the private Italian Hospital in İstanbul, so that he did not find the need to go abroad for his treatment, as is common for well-known and rich people in the recent years. He also talks about how some patients “brag about” how drinking nettle tea and eating apples cure their

cancer. Kanat mocks those people, since they seem to believe the people who tell them these “lies about alternative medicine,” but they still keep having their “proper treatment” in the hospital. Similar to Kanat, the cancer patients with the modernist view also have a strong attitude against the alternative/complementary medicine, which they consider to be practiced by “hypocrite charlatans who pretend to know as much as the real doctors,” in Gülsüm’s words. Gülsüm, a female breast cancer patient in her fifties, argued that folk medicine has historical and cultural significance, but it can not be compared to modern medical knowledge in treating people, especially in the cases of major diseases such as cancer. Gülsüm believed that modern medicine is the ultimate medical system of our times, and it has the most scientifically and technologically advanced methods of healing diseases, so that it is pointless to look for other sources for cancer treatment, especially if these sources are outdated. Both Altan and Yılmaz believed that if Atatürk’s reforms were fully completed in the educational and medical realms, alternative or complementary healing methods would be completely extinguished or would remain only marginal so that they would not be an issue to discuss.

Yılmaz also argued that the complementary or alternative medical practices are outdated, since they are systematically perfected by the scientists over the centuries in order to constitute modern medicine: “You see this drug that they use for my chemotherapy, right? The main source of it is plants, can you believe?...May be centuries ago, a witch, who had only two brown teeth left, was using that plant to cure diseases (He laughs). Then modern science and scientists came in and had a systematic research on the plants that were used to heal patients, and after hundreds of experiments they figured out the precise way of using this plant in order to obtain the chemotherapy drug... During medical education, the students learn all about this for six years, as well as all the organs,

tissues and cells of our body, including their tiniest details. What kind of a healer can have such a precise and detailed knowledge, which takes years to obtain?"

The patients' images of the healers in alternative or complementary healing systems as "hypocrits and charlatans" or as a "witch who had only two brown teeth left" are similar to the images that were used in the battle against religious healing in the 1930s in Turkey, which I discussed in Chapter 3. This battle, which took place until the 1970s, had a revival in the mid-1980s, with the rise of new Islamic movements. However, the first group of patients had less resistance to the alternative or complementary healing practices, which were not based on Islamic or Turkish folk medicine and which became recently popular, such as reiki, healing through positive energy and yoga. Altan said that his daughter attended a seminar on positive energy in Ithaca, U.S., and she joined a positive energy group when she returned to Turkey as well. Altan said that since she told him that this has a scientific basis, he allows her to "focus on him" and mention his name and his disease in the sessions that she was having with her group. Gülsüm also said that she tried yoga and reiki for a while during her cancer treatment, as a result of a friends' encouragement, and she said that they made her feel better psychologically, if not physically. The patients interpreted these healing methods as a part of the "modern Western life-style," although most of them had their origins in Asia, and did not see them as a potential threat to Turkish modernism and modern medicine, represented by folk and Islamic medicine.

Another reason that the patients who had the modernist attitude gave against the promotion of Islamic medicine was their interpretation of the Islamic rule that "there should not be anybody else between the believer and God" in the sense that the patients who benefit from the religious healing methods should not tell this to the other people.

Gülsüm talked about how her family always told her to keep her religious views and practices to herself, even though her father was an imam in a mosque in İstanbul: “Even though my father was a religious leader, he was also a strong believer of Kemalism, and he truly believed in the separation of the religious and secular world. The Religious world belonged to the house of our family, our home, and the house of the community, the mosque; and besides these two places you should never show off with your religious beliefs and practices...(How was this view reflected in your cancer treatment?) All through my cancer treatment, I prayed and visited the tombs of sacred people, but I have done these all by myself, and talked about it only when I am asked specifically, and of course never in the hospital... It is a sin to publicize or commercialize these practices for the cancer patients, which would be abusing people’s hopelessness and religious feelings.”

### **The Religious Patients and Their Views on Education, Science and Religion:**

The second group of patients believed that science and religion can coexist in the medical realm and had a more pluralistic view of education and modernity. This group was consisted of 6 patients four of whom had most of their treatment at SSK hospital. These patients described themselves as conservative or religious, and they do not like the popular label “Islamist” (*İslamcı*). Feriha, a breast cancer patient and a housewife in her sixties, argued that the word Islamist connotes an extremist political group, and it is “far from describing the people who just chose to live according to the religious principles.” Feriha described herself as a firm believer in Islam, and she told me not to tape record her voice, since it is not appropriate in Islam to have a female voice on a tape. She also emphasized that she regularly prayed five times a day, despite the physical difficulties

that she has and her daily treatment. She indicated that in the days when she had no energy left and could not move at all she was praying with her eyes and by muttering the prayers, “just like it is suggested by Muhammet.” For Feriha, Turkish people have lived in an Islamic way for centuries, and they cannot change this just because a group of politicians told them to do so. She contended that modernity and Islam can co-exist as in the example of Malaysia and Pakistan, where women do not have to be veiled and veiled women do not “experience the state’s oppression.” She knows about these countries through documentaries that she watches often on TV. She also prefers her “traditional headscarf” rather than the “turban,” because for her, young women wear the “turban” just for political and reactionary reasons. She argued that even Atatürk’s mother wore a headscarf, so the politicians around Atatürk must have convinced him to “meddle with what people should or should not wear.”

Feriha said that the doctors and nurses treat the patients “like her” differently at SSK, where she was having her treatment: “When they see a person like me, a middle aged woman with a long coat and headscarf, they immediately think that I am an ignorant villager. You can easily read that from the sour faces they make as soon when they notice me, but I was born and grew up in İstanbul and I am a high-school graduate, which is quite an achievement for the women in my age group... Even if my doctor explains something really simple, he asks whether I understand what he means afterwards, or even worse sometimes he speaks louder and slower, as if he speaks with a child or a foreigner! When they do that, I surprise them with how much I know about cancer since I keep following the news on cancer in the media.” Hamiyet also noticed the double-standards in the attitude of health care providers against different types of patients: “I wear my headscarf only when I work in the greenhouse that we have and when there is a bad

weather, because I do not think you should wear it to prove that you are Muslim. There are other ways to do it, like being an honest and good person... Anyway, it was very cold and snowy in my first visits to the SSK, so I wore my headscarf and I kept it even during my chemos. I realized that the nurses and doctors kept calling me “auntie” (*teyzeciğim*) all the time, and this has bothered me a bit, since they were not that much younger than I was. I felt that they treated me like an old and ignorant woman. They kept asking whether I understood the treatment plan and bureaucratic details, which I did, of course...But one day, I guess it was my fourth chemo, I had to go to a public office beforehand in order to get a license to build another greenhouse, so I wore a formal looking skirt and jacket, and I had no headscarf. At SSK, I noticed that the doctors and nurses treated me differently that time. Instead of “auntie,” they called me with the plural you (*siz*). They were more polite and spent more time with me, and after that day, that I began to wear similar outfits for the hospital visits. When it is cold I still wear my headscarf, but I take it off when I enter the clinic...I behave totally in accord with their double standards.”

The issue of the patients’ veil as creating problems in their interactions with health care providers did not come up in the narratives of the cancer patients who were treated in Güvercin, partly because there were considerably less veiled patients there. The modernist association of veiled women with lack of education, poverty and rural background is also not valid, particularly for the young generations of veiled women whose main aim is to partake in the social and professional life and play an active role in shaping the public sphere in Turkey. However, there were still very few veiled women among the middle and upper class patients at Güvercin hospital, partly since the hospital is situated in a secular neighborhood (Güvercin) in a secular district (Levent). Moreover,

the legal ban on the veil in the state institutions, including the hospitals such as SSK, put a psychological pressure on the health care providers in taking care of veiled women, although they cannot apply or impose that law in the hospital, because of the large number of the veiled patients and ethical concerns for the patients' well-being. Several "Islamist" newspapers, such as Zaman and Yeni Şafak, made news about the veiled women whom the doctors refused to treat in the state hospitals, and some of these news stories end with these women's eventual death because of the lack of medical treatment, since they could not afford the treatment in private hospitals. Although, the family members of those patients rarely brought these cases to the courtroom, and there was no news item on the family members winning any case, both the patients and health care providers whom I talked to were aware of such stories that put an extra pressure on both parties. In contrast, the mission of treating everybody first as human beings, and being open to the patients' psychological problems largely prevented the "SSK-style double standards," in Feriha's words, in treating the few veiled women there. I interviewed three veiled patients who were treated in Güvercin, and were all very happy to be treated equally well with the other female patients by the health care providers there.

For the second group of patients, SSK was just another state institution that imposes a certain life style and way of thinking to the people in it. Like Feriha, Hamiyet also said that Turkish modernity should not impose a certain dress code on people and that she wished to live in a modern society where both religion and science are equally respected: "I believe that the most important principle of modernity should be democracy, which should include the freedom of living in accord with your religion. If a woman thinks that she should wear a headscarf to prove that she is a good Muslim, then why should she not? As long as she would not force the other people to do the same, she can do that. I heard

that some doctors in the public hospitals actually refuse to treat veiled patients, and I know that any veiled nurse or a doctor cannot work in any public hospital. There are just a few private hospitals for them, the builders of which are religious businessmen. I hate this division in the society! What if a cancer patient needs an urgent treatment, and doctor refuses to treat her because of her headscarf! That would be a real pity, since that patient may even die because of it.”

**Religious Patients, Islamic Medicine and Folk Medicine:** The “religious” patients also question the labels of “Islamic” medicine and folk medicine, and their modernist associations with “backward” and “irrational” values, point of views and life styles. Hamiyet talked about the doctors’ association of “religious” medicine with the religious patients as an unfair generalization: “We live in a society that is 99% Muslim, so even if some of that 99% are truly secular or atheist, there is still a considerable number of people, may be several millions, who fully obey the Islamic rules...So, going to *hocas* to ask for his prayers and *muskas*, visiting the sacred tombs, drinking the water that is brought from Mecca and sacrificing an animal to avoid a common illness or after being cured, are just a part of many people’s lives here...Even if a patient does not believe in the efficacy of these practices, her mother or her neighbor does, and they would convince that patient to benefit from them. I believe that there is no need to be apologetic for practicing these methods, since people did it for centuries, and I saw their efficacy with my own eyes. Besides, if they were not effective, then people would stop these practices at some point, right?...I think many patients, even the ones whom the doctors consider modern or secular, use these methods, but the religious people are more vocal about it. Why would I hide it, just because the doctors are against them and they will be annoyed with me if I

tell them about these practices? Maybe the problem is in the doctors themselves, since they are alienated from their own people.”

When I ask her to give a specific example of the efficacy of “religious health practices,” she told me about her trip to a Hacı Bektaş-ı Veli’s tomb in Kırşehir: “Several years ago, my friend also had breast cancer, but hers was successfully treated after one and a half year of treatment. So, to thank Hacı Bektaş and God for providing good health she went to his tomb, sacrificed a sheep, prayed so that she and her loved ones do not have cancer again. My daughter and I also accompanied her to visit that tomb and say our prayers. In the tomb’s garden my daughter fell from the stairs. Her ankle swelled badly and became purple as well. A man, who worked in the tomb saw the accident and my daughter’s ankle...He cut a hairy piece of meat from the tail of my friends’ sacrificed sheep. He said some prayers and put that piece of meat right on the purple bruise on my daughter’s ankle. He wrapped it with a clean piece of clothing and told us to keep there it for two hours. At first, my daughter said that the meat made her uncomfortable and made her ankle itchy, but she kept it there for two hours. When we took it out, we could not believe in our eyes, since there was not trace of the swelling and the purple bruise. That was surely a sacred piece of meat.” This type of account of the efficacy of folk or religious medicine is quite common in the wards of SSK, as in the case of Gülten, a breast cancer patient in her sixties, who talked about how drinking water, which is brought from the pilgrimage in Mecca, cures the nausea she feels after her chemotherapies. Most patients at SSK and Güvercin hospitals, even the ones who are dedicated believers of Turkish modernism and modern medicine, such as Yılmaz, acknowledge the psychological benefits of folk or religious medicine, since “they fit well to our communal life and general world view.”

The patients who benefit from the alternative or complementary medicine do not distinguish much between religious or folk healing in conceptual terms, since most folk healing practices, such as Feriha's example of letting the bad or polluted blood out of the place where the tumor is situated, have also a religious or spiritual significance. Feriha saw this practice in the village nearby Şırnak in the Southeast, where she grew up, and said that it happened to a woman who was diagnosed with breast cancer in the city. She said that this can be considered to be both folk and religious medicine (*dini tıp*), since many people a *hoca* was there to say prayers while the village's midwife had a deep cut on the upper part of the woman's breast. They put the running blood to a special box, and poured it in a river, so that it "carries the evil disease to far away," and they also buried that box nearby that river after the ritual. However, folk medicine (*halk tıbbı*) also includes herbal remedies, which can be produced at home or in special stores in the old market places of İstanbul. The patients often underemphasize those remedies, by saying that they do not use them systematically, they use them because they do not offend elderly neighbors and relatives, and that they always use them together with their medical treatment in the hospital. Most patients believe that these remedies' contribution to their cancer treatment is only marginal and they take these remedies while having their chemotherapy or radiotherapy instead of completely dropping the modern medical methods, as some doctors at SSK alleged about the patients who regularly take these home remedies. The patients view those remedies as less effective, and emphasize that they do not have the same historical, social and cultural significance as the health practices of religious medicine. They are rather a part of everyday life, since they also use most of those herbs and roots in the meals as well, so they are not exclusive for the sick people. As for the newly-popular alternative or complementary healing practices;

such as yoga, reiki and positive energy, this group of patients either never heard of them, such as Gülten, or they were critical of them such as Hamiyet, who thought that “they were for the rich housewives who have a lot of spare time and money” to spend for these imported, fancy methods, which has nothing to do with the Turkish culture and history.

Similar to their reaction against the word, Islamist, the second group of patients also criticized the concept of “Islamic medicine.” Ayhan, a lung cancer patient in his thirties and a Ph. D. student in a theology department of a public university, explained that it is hard to call the religious healing as it is practiced in Turkey Islamic medicine, since it is mixed with folk medicine both in terms of theory and practice for several centuries: “As you probably know that Turks accepted Islam four centuries after it came out and they also combined it with pagan elements that they brought from Central Asia. The language of the classical sources of Islamic medicine is Arabic or Persian, which only a group of elite scholars could master thoroughly, so many healers in the Ottoman Empire had to read the translation of these sources, which also included the comments and additions of the translators, as well as their misunderstandings and omitting the parts they did not understand well... In an era, where written sources are few and unreliable, oral culture has become very important in the issues of health and illness. That is why we still here things like this *hoca*’s breath is so strong, he cured so and so’s cancer, even in the hospital, which is the cradle of modern medicine. When people have difficulties in relying on modern medicine, speculations and rumors on folk or religious healing become prevalent .”

Ayhan also argued against the typical modernist view that folk or religious healing practices will be extinguished eventually if everybody will be convinced to be modern through mass education in Turkey: “How on earth will you convince millions of people to

change their lives so radically? I believe that this is a social project of elite people and politicians that sounds like it is highly inspired by fascism. Of course I am not saying that Atatürk was a fascist, but he was just a naive soldier, who imagined the whole country as a battlefield, on which he can implement various strategies, some of which were highly surreal! ... I grew up in Istanbul and I went to the best private schools of the city, especially in the French high school that I attended we were bombarded with the modernist ideas everyday. It was so much that we did not want to hear any more about the French revolution and how it enlightened the whole world (He laughs)...But, when I began to study Islamic and Ottoman history in the university, I gained a new perspective and joined a religious group, who were also highly intellectual. We used to discuss Foucault and Edward Said, when they were barely known in other intellectual circles in Turkey. Therefore, we were highly educated people who chose to be religious and live in that way instead of going through the path of modernism. There were so many of us who did not internalize the modernist ideas, which were imposed in the schools and looked for an alternative path, which is more meaningful for our society and everyday life. So, it was no surprise that the first civil reaction against the straight jacket that the Turkish modernity wanted us to wear started in the universities in the 1980s, when young, veiled women wanted to attend university at the same time.”

As for his cancer treatment, Ayhan believed that nobody can decide about and impose the rules on his health practices: “When I was diagnosed with lung cancer, the things I had thought about in theoretical terms suddenly became concrete issues for me. I think cancer is the most medicalized disease in our era from its diagnosis to its treatment, so that nobody in their right mind, would want to treat his cancer outside of modern medical institutions, maybe just a few eccentric people who have other priorities than

their health...Last year, I had chest pains and coughed all the time, the first thought that I had was that I could have TB or lung cancer, and I have to go to hospital for tests to find out what I have. I knew that smoking may cause these diseases and I could not quit smoking two packs a day, and that was that straightforward... Besides my treatment at SSK hospital, I found a shelter in praying to God and practicing my religion...I prayed more often, obtained a *muska* from a highly intellectual *hoca* whom I trust fully, read religious sources on health and medicine and discussed them with my friends. These activities never hindered my medical treatment but they might have increased its efficiency by making me feel better. That is why I believe that as long as cancer patients have their treatment regularly in the hospital and whatever else they did for curing their cancer does not interfere with their treatment; other patients, doctors and nurses should not be judgmental on the alternative or complementary medical methods that the patients use. The patients should also feel free to exchange information about these methods with one another or discuss them with the doctors and nurses in the hospital. However, unfortunately health issues became a realm of an ideological battleground in Turkey...There is no way to confine religion into the privacy of the houses and reduce it to the individual acts as the modernists aimed for. Any religion is by definition is communal and public, and no one can change that.”

Ayhan’s words provide an intellectual background for the division between the groups of patients with different views of modernity, science and religion, as well as how this division is played out in the health realm. Although the patients in the second group were in general poorer, less educated and have closer ties with their rural background than the first, they resisted being categorized ignorant villagers whose religious beliefs are abused by “greedy *hocas*” by the first group of patients and the health care providers.

They have an alternative view of Turkish modernity where religious beliefs and practices, including religious healing methods, are not excluded or confined to the private sphere. The second group does not deny or exclude the basic aspects of Turkish modernity, and they accept the Turkish modernization as a given process, which should be open to criticisms, especially by the groups it excluded or discriminated against. They also criticize the reproduction of this exclusion and discrimination in the health and education, and construct their point of view through these criticisms. The cancer patients often connected the discussions on modernity to the political events in Turkey and in the world. I will discuss this topic in the next section and focus on how the patients' conception of cancer is related to their conceptions of global and national political affairs.

**III) Global and Turkish Politics and National Character:** During 2003-2004, when I conducted my fieldwork, patients and health care providers discussed several major political and social events extensively and related these events to the issues of health and illness. These issues were mainly the US intervention in Iraq, and the bombing of two synagogues, the British Embassy and the HSBC headquarters in İstanbul, which was committed by Hizbullah to protest Turkey's support for the US and Israel in Iraq. Besides these events, the first Turkish victory in a Eurovision song contest, and the Turkish national football team's third rank in the World Cup in 2003 were also among the popular issues at SSK and Güvercin hospitals.

In the large chemotherapy ward of the Güvercin hospital, where usually 6-7 patients are having their treatment at the same time, there is a TV, where the patients, the people who accompanied them, and even sometimes the health care providers watch the news, music and entertainment shows, and comment on them. On my first day in that

ward I was quite surprised by the blaring of the Eurovision-winning Turkish song from the TV and people watching carefully the song's video clip and commenting on the singer, Sertap Erener's performance. That song was the most popular song of the 2003 summer in Turkey, and in Güvercin hospital's chemotherapy ward. When the TV channels were showing its video clip again and again, the patients often asked the nurse to raise the TV's volume and stopped talking. Several patients also talked about Erener's battle with colitis and how she could not eat much during her illness. Begüm, a breast cancer patient and a housewife in her forties, talked about the association of illness treatment and losing weight: "In the earlier years of Sertap Erener's singing career, she was chubby, but then we read news about how she suffered from colitis and she could not eat much during her treatment. I guess, it must be like cancer treatment, since I have no appetite for two days after each chemo. However, Sertap must be a very strong woman, not only because she won her battle with her illness, but also she came out of the illness, with a great, highly slimmed down body! On top of everything, she realized the thirty-year old Turkish dream of winning the Eurovision." Several other patients and nurses also argued that Turkey can become a European Union member if more people as strong, talented and self-confident as Erener are raised, since the process of Turkish membership was also an important public issue in 2003-2004.

**Cancer and Turkish Independence:** The patients at Güvercin often praise being strong and independent in talking about the public figures, which they watch on TV, especially in the case of politicians who would make Turkey a strong and independent nation. Six patients at Güvercin and SSK emphasized that like the necessity to prove their strength and independence against the "others," including the health care providers and

people who could not bear hearing their problems, Turkey should also show its strong face to the “the West,” in order to maintain its independence. While talking about the US intervention in Iraq, Yılmaz praised the Turkish decision of not sending soldiers to Iraq, but criticized the Turkish companies that helped for the maintenance of the US army. He considered the bombings in İstanbul by Hizbullah as an “obvious result” of the Turkish cooperation with the U.S. In Iraq.

Despite the fact that they have a different political position (Yılmaz described himself as a skeptic leftist, and Ayhan as a religious person), both Yılmaz and Ayhan said that modern Turkey should not be a puppet of the United States or the European Union, and should keep its national characteristics, social rules and cultural values. Yılmaz argued that the U.S. Is the biggest empire of our century, and no matter how close Turkey or any other country would be to the U.S., it would not share the developments in positive sciences and medicine with the other countries: “Perhaps, the U.S. Is about to find the cure for cancer, or they might have already found it, but in any case they would not share it with any other countries, since it would be a top secret. They have to make sure that the rich people from all over the world should come to the U.S. In order to cure their cancer and spend thousands of dollars for that, or they may use these people as guinea pigs. Do you remember the former president of Azerbaijan, Haydar Aliyev? I was watching the news about his cancer since I was just starting my cancer treatment at that time too. First, his treatment started in Turkey, and I felt proud about it and the health care facilities here. Then, all of a sudden, probably some people convinced him to go to the US for his cancer treatment, and he went to one of those famous cancer centers there... He looked perfectly healthy when he was about to leave, waving to the crowd in the airport, and then he died all of a sudden in two months. They did not even explain the

details of his treatment. After that, I became even more suspicious about the U.S., after all it is an empire, where all sorts of secret projects take place.” Yılmaz also said that the superiority of the U.S. In medical terms widens the gap between rich and poor in terms of Turkish people benefiting from the modern medical services in their cancer treatment. He contrasted the poorest cancer patients who “suffer at SSK” with the richest cancer patients who are treated in the American hospitals, which have a five-star hotel comfort and apply latest medical methods and technology.

Ayhan also pointed out the disadvantages of Turkey’s being less developed in scientific terms than the Western countries: “This is like a vicious circle, all the top students of Turkey go to the U.S. since they have better educational opportunities there, and the gap between these countries in terms of scientific and medical developments widens because of this brain drain. This is also true for doctors. I know a cancer patient who sold his car to save money in order to go to the U.S. For his treatment, and he ended up having a Turkish doctor there (He laughs). I think this is sad and ironic at the same time.... The U.S. collects the best brains from all over the world, and then they manage the whole world not only in political terms, but also in medical terms as well...I cannot help but realize that so many new diseases came out in the last twenty years, and most of these lethal diseases mysteriously occur in the underdeveloped countries of Asia and Africa. The increase in cancer rates increase in developing countries also makes me suspicious. All that money for building high-tech labs and fancy hospitals can be also for a medical warfare, which no one could realize in other countries.” Ayhan observed that the medical warfare is his conspiracy theory is plausible, since the “Western colonial powers” had used the same strategy against the natives in America. He viewed this as the “dark face” of Western modernity, which Turkish modernists chose to forget or ignore.

This type of conspiracy theory is also common in Turkish society and the media. The U.S. is generally seen not only as the most powerful, richest and the most scientifically advanced country in the world, but also as a country that interferes with other countries' politics through wars and dominates their societies in social, cultural and medical terms. As in the example of the taxi driver, who argued that the U.S. can easily find the cure for cancer, if they did not prefer to spend their money on their wars in Iraq and Afghanistan, which I discussed in Chapter 3, many Turkish people believe that the U.S. controls the whole world in political, economic as well as the medical terms. The cancer patients I interviewed also considered European societies to be close collaborators of the U.S., and emphasized that they share the same social and cultural characteristics, even if the U.S. has more economic and political power since the 20th century. Gülsüm, who lived in Germany in her youth and who visited the U.S. several times, talked about a "common mentality" of the U.S. and European countries, which is also reflected in their medical realm: "I visited the hospitals both in the U.S. and Germany, and they were based on the same system foreigners did the hard and dirty work, and the doctors and nurses were European or American citizens...Even if they came from different countries, Germany and the U.S. honored them with citizenship, because they proved themselves as being extremely intelligent and hardworking. So, unless you are a superman, you clean the hospital's corridors and wards as a foreigner for a pathetic amount of money, and thanks to you everywhere becomes spotlessly clean, and patients and doctors appreciate it fully." Gülsüm observed that foreigners worked like "slaves" in the European and American hospitals, and the "Western science and medicine" profit from that work. Gülsüm argued that the "Western civilization" built this system, which abuses the "other" societies in many ways, having "a typical cold-blooded way of thinking."

### **Western Individualism and Coldness vs. Turkish Communal Support and**

**Emotionalism:** Like Gülsüm, Lerna, Selma, Abdullah, Yılmaz and Altan often generalized about “Western people” as being cold, selfish, “acting like robots that are aimed to maximize their own interests” in Lerna’s words, and contrasted them with the Turkish people whom they describe as emotional and unselfish. The “warm” and supporting interactions among Turkish families, neighbors and friends also provide “a safety net” through which the cancer patients’ major problems in the health realm are solved. Selma explained that since she had her own textile firm she did not have the state’s SSK insurance, which her doctor at SSK hospital recommended to her. She eventually managed to have the SSK insurance through her retired father, but it required her father to “run around for several weeks despite his old age.” He visited his old workplace, the SSK offices and hospital, in order to make the necessary changes in order to add his daughter to his insurance, and Selma was surprised that he did not complain even once during that process. Abdullah mentioned that his friends never left him alone at his house and in the hospital, and that his wife and daughter distributed the painkillers, which he could not use, to the other patients, who need them, at SSK. Yılmaz talked about how his family members and neighbors were concerned about his disease, brought meals and herbal teas, which they thought to be effective in curing his cancer. He added that, in contrast to Turkey, if somebody becomes sick in Europe or in the U.S. only the closest family members would care about him or her. However, Selma believed that helping each other is a typical national characteristic or a tradition, which is more associated with rural people and migrants, and that the Turkish society should keep this characteristic even when it will be fully urbanized and a part of the global capitalism.

Selma also related the process of her cancer treatment with the typical Turkish characteristic of being emotional: “In the first year of the high school I stayed in the girl’s dormitory, since my family’s house was far away from my school. I could see my parents and siblings only once or twice a month, and I missed them all the time, like all the girls in the dormitory. Some of us were not from İstanbul and had also problems to adapt to the city life...So, we had the “crying nights,” which were designated just for gathering, sharing our problems and crying as much as we could. I remember how well I felt after those nights, I felt light as a feather, sharing my problems with 40 other girls! After telling all of my problems, somehow they would bother me less... That is why I sort of continued this “crying night” tradition, although it seems a bit too girly and emotional. Especially, since the beginning of my cancer treatment, I gather the people whom I feel close, once every other week, and we start the whole dormitory routine again. I think being emotional makes you fully developed human beings, rather than a robot, and expressing your emotions to the right people at the right time and place is my best weapon against cancer. In these sessions, people also talk about other cancer patients, which make me feel that I am not alone.”

Selma’s account of “crying nights” suggests that there are particular times and places, where acting emotionally is acceptable for cancer patients, and only the people who are close to them can share the patients’ true emotions. Twelve other cancer patients shared Selma’s approach, by saying that they shared how they feel about having cancer only with few people whom they feel close to and that these people did not include any health care providers since the hospitals are not appropriate places to display one’s emotions. For instance, Hamiyet emphasized that she did her best not to show how much she suffered from cancer treatment, so that the doctors and nurses would not think that

she is a weak person. She also recommended other patients to be strong and calm in order to be taken seriously by the health care providers, who would do their best to get rid of the whining patients in their visits. This attitude is also a reflection of a clear separation of the public and private realms, through which, like being religious, the typical characteristics of communal solidarity and being emotional is confined to certain times and places in order to live in accord with modernity. These patients associated modernity with the “Western-style” formal social interactions, individualism and rationalism, which are more appropriate for the public domain rather than the private one, which should remain as typically Turkish and communal. This division is inevitably an idealized one, since it is impossible to compartmentalize the life as such, especially for the cancer patients who spend most of their times in the hospital and become emotionally close to the other patients and health care providers.

Altan has a different approach in associating the typical Turkish and Western characteristics with the private and public realms, since he argued that a good modern institution can also accommodate close and emotional social interactions as long as they do not interfere with its functions. Accordingly, the Güvercin Hospital is a good example of such institutions, since its health care providers and cancer patients are like one extended family, because of the health care providers’ helpful, warm and friendly attitude towards the patients. Altan contrasted Güvercin with the public hospitals where the cancer patients have to help each other on a regular basis to survive, since the health care providers there are too busy to help their patients’ psychological, economic and bureaucratic problems. Altan argued that the patients gradually learn how to display their emotions and control their excessive emotions in an institution, such as the Güvercin Hospital, where people should respect each other fully. According to Altan, being too

emotional is harmful both for the individuals' own life and social interactions, since it prevents thinking rationally and calculating the disadvantages and advantages of every step, which would be taken. He criticized the "typical SSK patients" who were constantly whining and crying in the corridors and waiting rooms, not being able to think that "all this crying and whining will demoralize themselves and other patients." Altan believes that both education and health should be "fully modernized in every possible way" in order to achieve a truly modern country, "every member of which are able to think and act rationally all the time, even if they acknowledge and share their emotions in a healthy way." Altan admitted that this is his dream, and he understood that probably it would be never realized every time he went to the public schools and hospitals and saw the chaos in the institutions, such as SSK.

Similar to perception of other social, economic and political problems in Turkey, several patients and health care providers are conscious about how a "Westerner" would react to the problems that the cancer patients experience, especially in the public hospitals. They are concerned about what would happen if a "Westerner" would ever see the mess and chaos in these hospitals. Being strong and independent as much as possible, as in the attitude of confining emotional problems to the private realm, also requires that these problems should be solved quickly *within* the country, before the Westerners notice these problems and tell the Turkish authorities how to solve them. For instance, learning that I study in the U.S. A doctor at SSK said that if an American stopped by the oncology clinic of SSK and saw the chaotic crowd over there, he or she would run away immediately and never ever even pass by a Turkish hospital again. Selma made a similar comment about a possible visit of the E.U. committees to SSK, which would result in their efforts to further delay and prevent the Turkish membership.

In all the three themes, namely urban and rural lifestyles, science, religion, education and modernity, and political affairs and national characteristics, the patients often contrasted their conceptions of “the West” and Turkish society, rarely giving examples from places other than the United States and European countries. Only Lerna said that she had a part of her cancer treatment in Argentina while she stayed with her sister who lives there, and said that the patients and health care providers were as emotional and warm as the Turkish people. However, not being able to speak in Turkish with them bothered her, since she cannot share her illness experience, and became one of the major reasons of her return to Turkey. As for Arabic and other Islamic countries, the patients such as Ayhan and Altan, emphasized the difference of Turkish Islam, which created a different, more liberated political and social environment than in these countries, and facilitated the introduction of modern Western thought. The comparisons between “the West” and Turkey, without including other countries, enables the patients to emphasize both the uniqueness of the political and social conditions of Turkey and its “in-between” position between the “East” and “West.” The “in-between” position is also valid for the cancer patients who appreciate the efficiency of modern medicine in diagnosing and curing their illness, but who also complain about the economic and bureaucratic difficulties that they experience in the hospital and double standards in the attitude of health care providers.

The three themes I have discussed in this chapter indicate how the patients relate public issues and debates in the Turkish society to their cancer and its treatment, as well as their conception of cancer in general. These issues and debates concern Turkish modernity, which is often considered to be a problematic process, and which may require many people to make dramatic changes in how they think and how they live. This

process is reflected and reproduced in the health realm in the form of patients' dilemmas about modern medicine and their "traditional" or "national" characteristics, and tensions between the health care providers and patients as well as tensions among the patients themselves.

## **Chapter 6**

### **The “Minor” Bodily Changes and the Personal Aspects of Cancer Patients’ Illness Experiences**

The cancer patients often talked about the public and private issues related to cancer and cancer treatment in the same interview. Many interviews included global or national political issues, such as the U.S. Invasion of Iraq, the brain drain from Turkey to the Western countries, and why Turkey could not develop or “modernize” in political, economic and scientific terms as in the West. However, these issues were also followed by personal and intimate discussions of how the patients cope with their bodily changes, and how these changes affected their everyday lives and interactions with the people who are close to them. In the interviews the accounts of public and private issues are embedded in or follow each other like a pendulum, and the patients associate their illness experience with these issues in different ways.

The typical bodily changes in cancer patients range from relatively minor problems such pain and aches, tiredness and lack of energy, nausea and weight issues, which I will cover in this chapter, to the loss of hair and breast removal, which are more radical changes in the body and which I will include in the next chapter. I contend that the bodily changes affect how the patients view their illness, and interact with other changes that cancer causes in their lives. I will investigate how the patients establish a hierarchy among their symptoms of bodily change before, during and after their cancer treatment, with respect to which of them are more important than others. The importance

of bodily changes is related to how they affect the patients' lives, their urgency in terms of notifying a doctor about them before the diagnosis or afterwards, sharing them with the people who are close to them and with other people, and their visibility to the patients and others. The less visible body changes, such as pain and aches, are difficult to share with other people and health care providers, although they may affect the patients' lives to a large extent. Therefore, dealing with less visible changes may constitute the most personal aspects of dealing with the changes that are brought about by cancer and cancer treatment. They are also informed by the medical and cultural conceptions of illness and sick bodies.

The patients often talk about the problems that they experience with the people around them, such as health care providers concerning how they become frustrated when their healthy friends compare their headache with theirs, or about how their doctors take those complaints for granted by considering them "typical side-effects of chemotherapy." Those frustrated reactions lead patients to constantly consider which bodily changes to complain about, whom to complain to, and how to do it. Which bodily changes should be shared with other people? Which bodily changes do the patients classify as private and personal? How does sharing affect the process of coping with cancer? The answers to these questions are also informed by the patients' socio-economic background, gender and age, as well as the hospitals they are treated in. Health care providers in different hospitals, as well as people around the patients, have certain views about what cancer patients should or should not do in their lives, and how they feel during their treatment, and these views also shape the patients' account of bodily changes.

The patients' response to these views and expectations reminds us of Talcott Parson's concept of the "sick role" (1970), where sick people enter into new set of social

roles, “since their usual roles have been seriously undermined, both by the physical limitations encountered in the disease and by the social identity associated with patienthood” (Wikan, 2000). However, the patients’ response to these views includes more pluralism, which gives the patients the opportunity to adopt and combine them in accord with their needs. Moreover, the relations between what is expected of patients and how they express their bodily changes are more dynamic and interactive, since the patients also have the ability to affect those views and expectations throughout their interactions. In that sense, the written cancer narratives have a more direct effect, since the people who no longer have cancer write those narratives retrospectively, in order to inform the readers about how they felt during their treatment, and in an attempt to change common social assumptions on cancer. Margaret Lock (1993) indicates that recent anthropological studies on the body tend to question and go beyond the “recalcitrant dichotomies” of nature/culture, self/other, mind/body, and knowledge/practice by focusing on the complex interactions of these categories in different social contexts. These studies also analyze the close connection among body, self, and society, and question the view of “the autonomous, rational, disembodied self as a gold standard for successful personhood.” I also share the perspective of these studies in these two chapters, where I will investigate the interactions among the individual, medical, social and physical conceptions of the body through cancer narratives. The most typical and inevitable bodily change during cancer treatment, which affects the patients’ everyday life is, perhaps, having pain and aches, the topic of next section.

**I) Problems of Pain and Aches:** Pain as a symptom of cancer because of health complications due to this disease, or as a side-effect of cancer treatment, is the least

visible change that the patients experience and have to cope with on a regular basis. Eleven cancer patients (eight lung cancer, one uterus, one breast and one liver cancer patient) said that the chronic pain that they felt led them to visit the hospital with the suspicion that they may have something serious, and they were eventually diagnosed with cancer. Thirty-three patients felt pain and aches for several days after the biopsy and other surgical operations, and for one or two days after each chemotherapy and radiotherapy session. These numbers show that having pain is a significant and almost inevitable part of the illness experience for cancer patients. Despite the prevalence of having pain and aches, like other bodily changes, the medical and personal meanings that are attributed to them, and the ways in which they are expressed differed from patient to patient. The variations depend on the patients' demographic characteristics, socio-economic background and the ways in which they internalize different cultural and medical conceptions of pain.

Several scholars explain that the experience of pain is shaped individually and culturally, despite the fact that medical authorities impose their own perception of pain, by suppressing or overpowering “all the other voices that offer us a different understanding of pain” (Morris, 1991). According to Elaine Scarry (1985), many doctors believe that the voice of the patients regarding their pain “must be bypassed as quickly as possible” so that their complaints can be translated into physical problems that can be detected through various medical technologies, such as the CAT scan and x-rays<sup>40</sup>. However, the author indicates that bypassing the voice of patients often means bypassing the patients themselves and the changes that pain cause in their lives. Scarry argues that

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<sup>40</sup> Elaine Scarry's views on pain and different ways of expressing it are discussed in a more detailed way in Chapter 2.

this problem also stems from the difficulties that people have in expressing their physical pain, and “political and perceptual complications” that arise when other people “speak on behalf of” those who are in pain. According to Scarry, there is a crucial difference between the perceptions of one’s own and another person’s physical pain, since other person’s pain is “vaguely alarming yet unreal, unseeable and as distant as the other galaxies in the sky.” This problem is also caused by the fact that having intense and severe pain resists language, and “causes a reversion to the pre-language of cries and groans.” Scarry describes witnessing the process where the person with pain is able to move out of that pre-language state and speak about her pain as similar to being “present at the birth of language itself.” She indicates that in order to be able to convey the expression of their pain to the other people and “objectify” it, many people refer to an object, as a weapon-like external agent, as in the example of “it feels as though a hammer is coming down on my spine.”

Referring to an object in talking about pain is especially valid for the lung cancer patients, as in the example of Yılmaz, who almost proudly stated that he smokes two packs of cigarettes everyday, even though he knew that smoking was the main cause of his TB in the past and his current lung cancer. Yılmaz said that he did not even try quitting smoking, despite the doctors’ warnings, thinking that then it would be too stressful to endure his cancer treatment, for smoking is one of the few things he enjoys in life. However, he said that especially since he was diagnosed with cancer, he felt “a burning pain” in his lungs, mostly at nights, after he smoked cigarettes back to back: “It feels like I swallowed a lit cigarette instead of smoking it, and somehow it reached my lungs and burnt them slowly from the inside.” He said that looking at the x-rays of his lungs also made him think in this way, since he can see the “dark and smoky” patches in

them, and that those patches made him think that cigarettes became inseparable parts of his body. Although Yılmaz came to terms with the burning pain in his lungs as an inevitable result of his smoking, he also complained about the “harsh and insensitive attitude” of his doctors at SSK when he expressed his pain. He said that the doctors told him that smoking that much, he had no right to complain about his pains, although they smoked as well. In contrast, his doctor in Güvercin empathized with him and talked about ways of quitting and reducing smoking.

In contrast to Yılmaz who blamed himself for his pain, Hüseyin, a lung cancer patient in his seventies, thought that it was unfair that he had a pain in his lungs, since he never smoked in all his life and he even stayed away from the places where people smoked. He described his pain as similar to “an acidic liquid that accumulates in his lungs and burns them,” which also refers to the main cause of his cancer, as in Yılmaz’s case. After Hüseyin retired from a car factory he opened a small workshop where he covered identity cards and other important documents with polyvinyl clothing (PVC). He worked with certain acidic liquids, the fumes of which, caused lung cancer, according to his doctors. He said that he had to work more after he retired, since he had to take care of his three children, but he was angry, since no one warned him that working with PVC causes cancer. Similar to Yılmaz and Hüseyin, six other cancer patients (four male and two female patients) associated their pain with the cause of their cancer and talked about smoking and chemicals that polluted the air. This association enabled the patients to talk about their pain in more concrete terms and legitimized their expression of it, especially for the people around them and for health care providers.

**Pain and Gender:** Most women do not have pain in their breast in the earlier phases of cancer, unlike the male lung cancer patients who come to the hospital mostly with the complaints about their chest pain. However, the lack of pain in the female patients' breast is often disadvantageous for women, since it causes a crucial delay in detection of cancer. Ten breast cancer patients explained that they did not worry about the swellings or roughness in their breasts, since they associated having cancer with "having an unbearable and constant pain," as Gülsüm said. They associated the anomalies in their breasts and rare cases of slight pain with "womanly issues," such as having menstruation, menopause or even "not breastfeeding for a long time" in Feriha's words.

Feriha explained that she had two daughters when she was in her twenties, and she and her husband decided to have one last attempt at a son when she was 38 years old. She said that they were "overjoyed" when they had a son at that time and she breastfed her son for three years. Her children made her body become used to producing milk and to breastfeeding: "My body was producing milk for my babies in my twenties, thirties and even in my early forties, of course there were a few year-breaks in between each breastfeeding time, but I felt that it became some sort of a pattern in my body...I guess I stopped breastfeeding when I was 41 or 42, then my usually healthy state changed dramatically in few years. Before turning fifty, the first signs of menopause appeared, and at that time I began to feel hard bumps in my breasts, which also gave me pain sometimes. I thought that these were normal things, since my breasts were used to producing milk and breastfeeding for a long time, and when that long phase ended they could not adapt to it and began to produce milk-like liquid substances that cluttered my veins. I expected that they would go away eventually when my body would become used to not producing

milk for a long time.” This explanation led Feriha to wait six more years before visiting a doctor for the problems in her breasts. That is also in accord with the cultural view of unselfish women who live for their families and who take care of their “womanly problems” by themselves, without bothering anybody else, described in Chapter 4. Even if they have pain occasionally, as long as it is not intense and frequent, which they associate with cancer, they only share it with their close female family members, mostly with their daughters, and friends.

The association of pain with “womanly issues” also normalizes it for some cancer patients, who thought that it was inappropriate to talk about that pain with other people, including health care providers. Selma explained that since her early teenage years she had severe, cramp-like pains in the area where her uterus is both during and after menstruation, and she thought that the reactions she had from her mother and older sisters when she told them about her pain led her to accept it “without making a fuss about it”: “I have six other sisters and five brothers, and you really had to have a serious health problem in order to whine about it... Of course, I could not talk about my pain when my father or brothers were around, and complaining about my pain to my sisters and mother was also difficult, since I knew that they all had menstruation and none of them ever complained about having pain. I did not want to be singled out as the spoiled youngest child, and when I mustered up the courage to talk about my pain with one of my older sisters and my mother, they just shrugged their shoulders and said that it is both normal and inevitable. They gave me an aspirin and told me to keep my stomach warm... Later on, the same pains became more severe and did not always coincide with my menstruation, but still I thought about the words of my mother and sister and did not go to a doctor for several years. When I went to doctor for these pains and eventually learned

that I have uterine cancer and that those pains are the most typical symptoms, I felt so bad about not taking those pains seriously for years, and began to warn all the other women around me about those pains. I even forced my sisters to visit hospitals for pap-smear tests and luckily they were healthy.” Selma’s story also indicates that women who live in crowded households also have difficulties in talking about their personal, “womanly issues,” including their pain, since they do not have enough privacy. Selda Merey (2004), a head nurse in a private hospital, who conducted research and educational seminars on women’s self breast examination, said that women who live in crowded households also rarely examine their breasts and note the changes in them because of their lack of privacy and suffer most from the delays in their cancer diagnosis.

Nine female cancer patients, eight of whom were treated at SSK, said that they often took for granted their pain in or around their reproductive organs, since it is considered “yet another difficulty of being a woman” in Hamiyet’s words. Hamiyet said that complaining about these typical womanly problems to the other people or even to oneself could be considered to be complaining about being born as a woman and, even worse, challenging God’s decision on the gender of babies, which is a major sin. This view also confirms the subservient position of women, who choose to neglect their own health problems, and concentrate instead on the problems of other family members, such as their husbands and children. Ayla talked about how she “naturally” prioritized the problems of her daughters and husband over hers and tried not to dwell on the pain in her breast since the earlier years of her marriage: “Both my mother and my grandmother were running to help everybody in the family, and I do not remember that they ever complained about their health. Therefore, I guess, I unconsciously followed their example. What else could I do? When your husband came from work with a sullen face,

or when the first tooth of your little baby came out, you automatically forget your own problems and concentrate on theirs... Now that I have had a cancer treatment for the last two years, which really wore me out, I wish I could have been more selfish back then, but I guess it is a bit late now to change our family patterns, since my daughters still come up to me even for their tiny little problems although they are grown up women. Although, they take good care of me when I feel sick, will they learn how to be really unselfish when they will be mothers themselves?"

According to the Division of Education cancer in the Ministry of Health, neglecting these problems is common among women who come from disadvantageous backgrounds and who have very little or no formal schooling. As I discussed in Chapter 3, several cancer foundations issue lists of health problems for women which require them to visit a doctor, and organize campaigns to encourage all women above the age 18 to have regular gynecological check-ups. However, these campaigns, which became more prevalent in the late 1990s, mostly reach women from the middle and upper classes, who had formal schooling and who work, and thus their lives are already medicalized to some extent (Merey, 2004). The campaigns also fail to acknowledge to a large extent the family dynamics and cultural factors which lead women to take their pain for granted, neglect their health problems in general. They also impose certain guidelines for *all* women, regardless of their socio-economic background. Only seven female cancer patients, all of whom were treated in Güvercin, said that they became aware of those campaigns *after* their diagnosis, and four of them found them "somewhat useful" in raising awareness on cancer. Ayla, who is among those four patients, said that those campaigns taught her to take note of her health problems, such as regular or ongoing pains, even if they do not bother her that much, since they may be symptoms of a serious

health problem, such as cancer. For her, taking pain seriously meant visiting a doctor, or sharing her health problems with her family members and friends, whose medical knowledge and experience she considered reliable. Ayla said that although these people are not necessarily doctors, nurses or pharmacists, they or their close family members who had chronic illnesses made them often visit hospitals.

**Expression of Pain during Cancer Treatment:** The cancer patients also experience difficulties in talking about their pain during cancer treatment. The fact that there is a direct correlation between their pain and illness can be both advantageous and disadvantageous for the patients, depending on the social and medical views on cancer and cancer patients. Having cancer legitimizes the patients' complaints about their pain to a large extent, but that does not necessarily mean that they can talk about their pain more easily than the people who are defined as healthy in medical terms. Figen said that her cancer led her to divide all of her friends and family members "with a sharp boundary between them" as people close to her, whom she can talk about the pains she had in her breast and stomach after each chemotherapy, and people who just *seemed* to be close to her. For her, most of her friends and some of her family members in the second group seemed concerned about her health. However, since they are healthy, they did not want to hear about the health problems of a cancer patient in detail: "When they ask me how I feel, I think that they are really sincere and I begin to talk about the pain that I keep having, but as soon as I say one or two sentences they interrupt me by saying "oh dear, it must be so hard for you" or they begin to talk about other cancer patients they know. I know that they only ask about my health in order to be polite, and I answer them very briefly."

Figen explained that she could easily talk about the pains that she had with her close family members and friends who also helped her by taking her to the hospital, providing the drugs and dealing with bureaucratic matters. However, she also felt reluctant to talk about her pain with these people, especially when her cancer treatment lasted much longer than she expected: “These people suffer with you all the time. You become a small team in those SSK trips, so that you eventually forget who has cancer among them. (She laughs), but they suffer almost as much as I do. I feel reluctant to make them feel even worse. I eventually realized that my pains are episodic, so I often just wait by myself for those pains to go away.” Eleven other cancer patients (six female and five male) from different socio-economic backgrounds also said that they talk about their pain only with the people with whom they feel very close. Altan, who was treated mainly in Güvercin, said that he did not want to show his weak side to the people who are not really close to him, and that he wished that only his close family members knew about his battle with cancer. Later on, he also appreciated the close care and concerns of several doctors and nurses at Güvercin, whom he added to his “close family.” This is also in accord with the patients’ wish to be and, at least to look, strong and independent, as I discussed in Chapter 5.

Twelve patients said that they do their best to see that their pain does not affect their everyday lives and interactions, similar to the way some of them “deny” having cancer, as I discussed in Chapter 4. They emphasized that they need to be emotionally and physically strong so they can go on with their “normal lives,” even though they are in pain. Linda Garro (1984) and Mary-Jo Delvecchio Good (1984) note that having a stoic approach towards the experience of pain is common among White, American women, with a chronic illness. Those women discuss their pain in “a-matter-of-fact” way and

suppress its significance, as well as their emotional needs caused by their pain. Garro (1984) observes that chronically ill people associate their pain with “losses, unrealized goals, disappointments and lack of control,” and that they contrast it with the meaningful and creative activities in their lives, such as their work. Similarly, several Turkish cancer patients’ downplay their pain and how it affects them in order convey the message that they are still strong and independent people, despite the fact that they have cancer.

According to Gülsüm, both health care providers and her friends thought that it was inevitable that she had pains during her treatment, and that is why they did not want to listen to her when she talks about her headache and the pain in her joints, which she felt for a few days after each radiotherapy session: “It was like I could feel every joint in the bones of my body, especially in my chest and arms. It was also an awful feeling...It felt like I had a hard physical labor for hours, or I have not moved at all as if I my whole body was stuck in a tight cast for hours. It is hard to describe...People did not want to listen to me when I talk about these pains as well (Why?) Because both the people in the hospital and most of my friends were very insensitive. The doctors and nurses thought, ‘If you have cancer and you are having a cancer treatment, *of course* you will have pains. So why do you make such a fuss about it?’ Most of my friends also expected that I would accept those pains as a natural part of my treatment and so I do not complain about them. Once, I never forget, I was talking about the pain in my joints and a friend of mine interrupted me by saying ‘Oh, I often have very bad headaches too.’ I was so shocked to hear that she was comparing her headache to my pain, since her health was just perfect! Maybe she just wanted to empathize with me in a weird way, or she thought that since she was healthy, her headache was something mysterious, therefore something worth talking

about, unlike the pain and aches that I had!!! I never talked about my illness with her again.”

There is also difference in the attitudes of health care providers at SSK and Güvercin hospitals towards the patients who talk about their pain. Yılmaz, who visited both hospitals for his cancer treatment, argued that the SSK doctors and nurses do not want the patients to talk about their pain too much, since they “have no tolerance for the complaining patients.” In contrast, Yılmaz believed that since Güvercin’s health care providers aimed at providing the best quality cancer treatment, they were concerned about the pain caused by the treatment and tried to find ways of reducing it: “Each time, I went to SSK for my cancer treatment, doctors and nurses asked me whether I have any complaints about my health, but they asked this question because it is a formality and they have to do it. You could easily see that they were bored when they asked you and waited for you to answer them in just one or two sentences. When I talked about that burning pain in my lungs, they interrupted me and only said that it is normal and typical for a heavy smoker like me. A young doctor even told me that every medical textbook describes that type of pain as the standard lung cancer pain, and I asked him whether they have any therapy to lessen that pain. He replied, rather impatiently, that I will not have those pains when my cancer treatment is completed successfully. Of course, that reply did not really comfort me, since it has been two years since my treatment has started, and I have no idea when it will be over. Luckily, in Güvercin, the doctors and nurses are more concerned with my pains. Since I cannot use the typical pain killer drugs during my treatment, a doctor in Güvercin did some research and found the specific drugs, produced for the patients who have same condition as me. He also gave me tips about reducing

smoking in a less stressful way, like drinking green tea every time I badly need to smoke.”

Most health care providers at SSK had a “blame the victim” attitude about the cancer patients’ behaviors, such as smoking for lung cancer patients, and not having regular check-ups for the breast cancer patients. Therefore, they did not want them to “complain too much about their cancer, especially their ordinary pains and aches,” as one of the nurses at SSK said. A male doctor at SSK explained that the Turks are “already genetically oriented to have cancer and they do everything to invite it. Then, according to him, they become devastated when they learned that they have cancer and relate every health problem they have to it: “Recent research showed that Turks have every single cancer gene that exists in the Balkans and Middle East, since we have a heterogeneous society in terms of ethnic groups. When Turkish people gain relatively more money, what do they do? They do everything to invite cancer actually (he laughs). They smoke more, they eat more meat and greasy processed food, as you see in the rampant increase in smoking and obesity rates. However, they still avoid hospitals, until they become terribly sick. So most cancers we detect are in their second or third phase, which is a pity, because it is much more difficult to cure these developed cancers! I actually become frustrated when patients tell me about their minor, ordinary pains and aches. I sometimes tell them ‘if you could come to the hospital much earlier, your cancerous tumor could be taken off with just one operation and you would be perfectly fine afterwards. In a way, I think they have no right to complain about the pain that they have during cancer, when all the media shouts out loud for years about the importance of early detection and the harmful effects of smoking. We just aim at curing the cancer they invited and they only have to endure the side-effects of the treatment, which we try to reduce as well most of the times.”

The attitude of health care providers also depends on whether they can find a medical explanation and confirmation for the patients' pain, as in the case of Yılmaz, or they often categorize the pain as "simply psychological." Hamiyet explained that the doctors at SSK could not figure out why she had headaches after each radiotherapy and they eventually considered them as "simply psychological" and ignored them: "My head, especially the area around my eyes, was aching for one or two days after each radiotherapy session. When I talked about that pain with my doctor, he looked at me rather puzzled. He said he never heard of such a pain and made a telephone call to another doctor. My doctor said something like 'yes, yes, of course I thought it is psychological as well.' After he hung up, he told me that I have pains because I feel to stressed out before my radiotherapy and told me to do something relaxing and fun before and after the sessions, like taking a walk, seeing a friend and shopping. I felt angry and thought that he was making fun of me, since my health would never allow me to do these things." The difficulties cancer patients have in expressing their pain in their social interactions and in medical institutions, often lead them to cope with their pains and aches "by themselves," as nine patients stated. Although, these patients' self-reliance in coping with pain and aches confirms their self-image as being strong and independent, it also prevents them from having enough social and medical support in coping with cancer and furthers their marginal position as "cancer patients."

Surprisingly, the written illness narratives cover this issue rarely, partly because of the common view that the patients have to deal with their pain and aches by themselves. Only three breast cancer patients wrote about having pain and how it led them to seek medical help, or to seek other ways of reducing it. Similar to the accounts of Gülsüm and Feriha, a well known bar owner and architect, Ayten Özer (2006), explains that she

avoided visiting a doctor for four years, despite the fact that she could easily feel swellings in her breasts. When she eventually had pain in her breast she thought that “the tumors grew enough to see a doctor” and she should face with the reality of having cancer. Asiye Salkim (2006), a 29 year old journalist, also thought that it is “unlike her” to have cancer, partly because of her young age, and avoided seeing a doctor for “a couple of years,” despite the fact that she had regular pain in her back and arms. Esin Özbek (2006), an accountant in a private hospital, talks about the pain she had after her breast and lymphatic tissues in her arm were removed. She explains that she coped with this pain by starting yoga and meditation, despite the fact that the doctors around her did not agree with each other about the harms and benefits of yoga and meditation for such pain.

## **II) Problems of Tiredness, Lack of Energy and Depending on Other People:**

Similar to the pains and aches, feeling tired during the cancer treatment is also a common complaint of cancer patients and it affects their everyday life, professional career and social interactions significantly. Fourteen patients explained that they felt very tired after the chemotherapy and radiotherapy sessions, and they had a lack of energy in general throughout their cancer treatment. Twenty five out of fifty patients complained about feeling tired and being bedridden for a couple of days after their chemotherapy, but only five of them, who had their treatment in Güvercin, knew that this is mostly because of the sedative drugs that they take to decrease their nausea and pain associated with their chemotherapy. Among them, Selma was glad that her doctor explained this to her when she asked him why she felt so sleepy after her chemotherapies, since she thought that feeling tired was easier to cope with than feeling nauseated and having aches. Three patients also described that they felt sleepy and could not do anything but sleep for

several hours after their chemotherapy. Among them, Hamiyet described that she felt as if “there was something very heavy like a piece of lead on her eyelids” and that is why she could not help but close her eyes and fell into sleep. The written illness narratives also include descriptions of how the authors felt tired after their chemotherapy, as in the example of Tülay Sağlam (2005), a journalist who specialized in health news, who in contrast to Hamiyet, had difficulty in sleeping despite her tiredness. Sağlam describes her tiredness as similar to being “paralyzed,” since when her extra blanket fell off, she did not have the energy to take her arm out of the bed sheet and take it back.

The cancer treatment, which often continues for several months, leads the people who have cancer to see themselves first as “cancer patients,” since being sick also gradually affects their other personal characteristics, such as their gender, age and occupation. Seven patients said that they learned to accept their identity as cancer patients and live their lives accordingly. In order to do that, they had to make certain adjustments and have a “new and slower rhythm” in their lives, in Füsün’s terms. Füsün, a breast cancer patient who works as a researcher in a large-scale private firm, explained that she works in a five-people team of researchers in her office and she could delegate her job to them under certain conditions: “Now my work life is less hectic, since I cannot afford working day and night as a cancer patient. Instead, I feel like a machine with on and off buttons (she laughs). I have three chemotherapies per week, which usually take place on Monday, Wednesday and Friday mornings. On those days, there is no way that I can go to work. After I return from the hospital, I sleep or just lie down for several hours. Then I make few necessary phone calls or work on my computer and reply to the urgent mails. Tuesdays and Thursdays I usually do the work of two people, since I want to take the burden off my friends who covered for me during the days of my chemotherapy. I

sometimes go to work on Saturdays too. On Sundays, no one can make me work or go to the hospital, it is the time for me to spend with my parents, sisters and my friends, doing the things I like, such as watching a movie. Having this rhythm for quite sometime, I really became used to the idea of living with cancer, so my periodic lack of energy does not bother me anymore as it did after my first few chemotherapy sessions.”

Most female patients in the age group of 56-75, who did not work, also found ways to adjust their rhythm of life according to their cancer treatment and to motivate themselves to continue with their everyday life. For instance, Ayla, a female cancer patient and a housewife in her sixties, who cooked a different vegetable everyday in order to make her blood thicker during her cancer treatment said: “Both my late husband and daughters loved meat, and that is why I cooked meat every day for years...But when my husband died of heart attack in his early fifties and I was diagnosed with cancer, I decided to change our dietary habits. From the news articles on cancer and my friends who have cancer patients in their family, I learned that the vegetables with dark green leaves and from the cabbage-family make your blood stronger and thicker, so give you more energy and strength to cope with cancer. Then I made a list of seven vegetables in those categories and began to cook one for each day during my chemotherapy. For instance, Monday is the spinach day, on Tuesdays I steam broccoli, on Wednesday I make cabbage with minced meat, and it goes on like this... On Saturday we eat brussel sprouts, the taste of which we actually like (She laughs). Before making that list, I did not know that there are so many vegetables! Now, every morning, I wake up and the first thing I think is the vegetable of the day and how I am going to cook it. This gives me a purpose that motivates me to start my day even if I feel tired and reluctant to go out of the bed.” Health care providers at Güvercin and SSK also use the expression “making the blood stronger

and thicker,” when talking about the operations that increase red blood cells in patients’ bodies and strengthen their immune system. The health care providers mostly use that popular cultural expression and briefly explain what it is in medical terms to the patients. Most patients evaluate the medical operations of “making the blood stronger and thicker” as useful not only for their cancer treatment but also for their general physical strength and resilience.

**Gender Issues and Problems of Depending on Other People:** The health care providers and “model patients” who often appear in the media often advise cancer patients to be active and productive as much as possible in order to “stay connected with life,” as a female doctor in Güvercin said. The doctors also emphasize that the patients should not quit their jobs, and should have new hobbies that they enjoy and they can afford to pursue during their cancer treatment, despite their lack of energy and the time required for treatment. However, this advice may not be possible for many patients who are considerably affected by their cancer treatment in physiological and psychological terms. The longer the patients’ cancer treatment lasts the more their tiredness becomes chronic, and most patients become bedridden for some time during treatment. Their chronic tiredness makes the patients even more dependent on the people who are close to them and who already help them in their hospital visits and in their daily lives. How the patients evaluate this further dependence is related to their dependence on other people before their diagnosis and how they viewed it. Several patients emphasized their uneasiness, since the self-esteem of most patients largely depends on their self-image of strong and independent people, as I discussed in Chapters 4 and 5. This is especially true of the female patients in the age group of 25-55, and also male patients of the same age

group, but women over 55 often have different views on working and being dependent on others. For instance, Ayla, who is in her sixties and who has never worked, explained that she took care of her three daughters for so many years and that it is her daughters' turn to take care of her now, since she is "old and sick." She described this fact as "the inevitable phase of the life cycle," and therefore, she did not seem to be particularly bothered by the idea that she had now less energy and became more dependent on other people.

Most women in the age group of Ayla also shared her view that now it is the turn of their healthier and younger relatives to take care of them, both in financial and practical terms. Fourteen out of twenty-five women in the age group of 56-75, whom I interviewed, held this view; and they were either retired (three women) or never worked (eight women) other than helping their husband in the fields and flower gardens without having any payment. Only six of these 14 women finished high school, five others were primary school graduates, and the remaining three had only a couple of years of schooling. Twelve of these women have grown-up children and children in-law who helped them to take care of themselves both before and during their cancer treatment, which made them ready to adapt to the idea of "being dependent on others while being sick." They also rarely complained about their lack of energy and how it affected their lives, and when they did, it was about their social life and interactions. Only three of these women worked, two of them as a high school teacher and the other as a cleaning lady.

In contrast, four out of six women, who were in the age group of 25-55, worked on a full-time basis and embraced the motto of "being strong and independent cancer patients" more fully. However, similar to Füsün, they also admit that certain adjustments at work are needed, so that they can work and have cancer treatment at the same time.

Along with Füsün, three of them were concerned about their temporary absence at work due to their treatment and how it may affect their careers in long term, because of “their general image of a sick person who cannot fully dedicate herself to her work,” in Ceylan’s terms. Ceylan, a 34 year old breast cancer patient who works in a private firm, is concerned about whether she will get a promotion at the end of the year, although she thought she was successful in her position. She also thinks that her sickness will affect her chances of being a manager, since she works in a small firm, where everybody will remember her disease and treatment “for years.”

Out of fourteen male cancer patients, who were in the age group of 56-75, eleven men retired, but seven of them took other jobs after their retirement, in order to take care of their wife and children. Six men in the age group of 25-55 were all working or studying. Among the men who worked, only Caner, a stomach cancer patient in his early thirties, who worked as a sales manager in a private Turkish food company, complained that his lack of energy affected his work life: “I am currently having radiotherapy twice a week, and even on the days when I have treatment I do my best to go work... When I am too tired to work, I sit by my computer and pretend to work, and sometimes, I just close my eyes and sit in the bathroom or in cafeteria for ten-fifteen minutes when not many people are around (Why don’t you go home, when you feel tired?) I simply cannot, since there is a big competition in our department, I am now a sales manager who is responsible for Istanbul and I want to be responsible for the whole Thrace region in few years. However, as far as I know, there are at least five people, who compete for the same position, and I don’t want them and my superiors to have an impression that my illness affects my performance at work.... That is also why I never talk about my illness with my colleagues, or I just say ‘I am fine’ when they ask how I feel. I have managed to have an

OK performance at work so far, but I just hope that my health condition will not get worse or that I will not have another set of chemotherapy or radiotherapy.” Although the accounts of Caner and Ceylan sound similar to each other, Ceylan has also to cope with “extra pressure” from her colleagues, who thinks that she has to marry and have children soon: “I try not to talk about too much about my private life, but several of my colleagues know that I have a boyfriend, and he often takes me to the hospital for my treatment...They always say that our relationship will become stronger because we battled against cancer together, and we will marry and have children right after my treatment. They also give examples from the people they know, who had married and have children right after their treatment. Maybe they think that I am concerned about these issues and they try to make me happy, but I only become more worried when they say these things. I think they also imply that even if I am fully recovered, I will have to deal with the issues of marriage and having children, which will distract me from my work again.”

The accounts of male and female patients in the age group of 56-75, also differ on the issue of how their lack of energy affects their life and dependence on others. Unlike the female patients, all four male patients who stopped working before their cancer diagnosis, were bothered by the fact that their lack of energy due to their illness and treatment makes them even more dependent on their wives, children and children in law. For instance, Mehmet, who is a colon cancer patient in his seventies, said that he feels upset when he lies in the bed because he requires long term care by his wife and five children, and by his son in-law who takes him to the Güvercin hospital for his chemotherapies. He said that he was not used to being dependent on other people since he is person who “believes in the value of working”: “I grew up in Skopje, Macedonia

and went to the vocational high school there. In that school I learned all about repairing cars and buses... Working and helping other people were very much valued both in our family and that country in general, when I was growing up. Therefore, I worked very hard for decades, repairing busses in Skopje and then in Istanbul after I migrated with my wife. I worked for IETT (The main public bus company in Istanbul) until I was 65. However, even after my retirement, I stayed very active repairing the roof and the plumbing systems of our house in Istanbul and summerhouse in Gümüşyaka. I also worked in the gardens of these houses and managed to raise most of the fruits and vegetables that my family consumed. Sometimes, my children and my son in law tell me that I should have worked less hard in my sixties in order not to have cancer now. However, if I stay idle for five minutes, I feel useless. Therefore, it is really painful for me not to have any energy because of cancer, and I also feel bad when my wife, children and son-in-law, who have to stop what they are doing just to take care of me.” The men in the age group of 56-75 do not consider being dependent on other people as a part of natural life cycle as women of that age group do, because of their self-image of the main provider in the family independent of their age and health situation.

Another difference between the male and female patients from both age groups is their attitude towards working and being independent, as I also discussed in Chapter 4. Five out of seven women who work emphasized that they work mainly in order to maintain the living standards they were used to before their marriage, or to achieve better economic standards. Four of these five women added that they can quit working if their cancer became worse or they could find other sources for money, such as an inheritance or help from a cancer foundation, whereas only three out of fourteen male patients who worked talked about the possibility of quitting their jobs if their illness becomes worse.

The difference between the female and male cancer patients in terms of complaining about the effect of their lack of energy on their performance at work and dependence on other people is related to the typical, patriarchal view, which cuts across classes and urban-rural divisions, according to which men are “breadwinners” and women are “nurturers” of their families. Despite the policies of Atatürk for the integration of Turkish women to the formal education and professional life and idealization of workingwomen in the late 1920s and 1930s, many Turkish women still claim that they worked only because of necessity. The economic contribution of women is downplayed in most families as superfluous, even if what they gain is a significant amount for the maintenance of the household (White, 1991). The feminist movement, which has been active in society since the mid-1980s, aimed at changing this “seemingly natural” division of labor in the society, and they targeted the law that stated that the married women should have their husband’s permission in order to be able work, a law which is abolished as late as 1992 (Özyeğin, 2001).

Despite the efforts of feminists and legal improvements, Gül Özyeğin (2001) still points to a polarization among working women in Turkey, where the two types of working women closely depend on each other. There is a high rate of women in the professional and academic world, on the one hand, and many women also have low-paid, mostly informal work on the other. Özyeğin (2001) states that a large group of women who migrated to the city from the rural areas made it possible for professional women to fulfill their “nurturer” role in their families by providing cheap domestic services, such as cleaning, cooking and babysitting for the professional women. This polarization and co-dependence has sustained the typical division of labor in the families, which is based on gender, and has excluded from the workplace a considerable number of women from the

middle class, who still see their main duties as housekeeping and raising children. The upward mobility of recent migrants also makes them internalize the middle class family values, since most migrant women also eventually give up working and become housewives when their husbands find a well-paid job and they save enough money (Özyeğin, 2001). Despite this polarization, most women in their twenties and thirties, grew up in the 1980s and became influenced by the feminist movement, which has promoted the integration of the women from different socio-economic backgrounds to the formal educational system and professional life. That is why their self-image tends to be more “strong and independent patients” rather than the “nurturers” of the family who will be taken care of their children in an old age.

The women in the age group of 25-55, are also more informed by the view of an optimistic and self-sufficient “model patient,” which is promoted both in media and medical discourse, than the older patients. All women in that age group said that they looked at the internet sites on cancer, including the ones where the patients support each other, followed the news on cancer on TV and printed media, and had read several published illness narratives written by the cancer patients in their own age group. In contrast, only 6 women in the age group of 56-75 said that they follow the news on cancer in the newspapers and TV, and two women said that they read published illness narratives. Since the media generally includes more doctors’ views on cancer and cancer patients rather than the patients’ voice, it also serves to internalize the medical discourse on how the patients should behave, including what and how they should complain to the doctors during their treatment. For instance, they suggest that the patients should make a brief, written list of their complaints, starting from the most important ones, bring this list to the

doctor's visits for each examination, in order to be as clear as possible while talking to the doctors and not to miss any important complaint.

The health care providers at SSK and Güvercin were also more tolerant of the complaints of women who work, especially regarding their tiredness and nausea, and they claimed to understand whether a woman works or not before even asking about it, as a male doctor at SSK claimed: "The women who work, even if they clean the houses of other people, know how to dress properly for their hospital visits, at least they do not come as how they are dressed in their house. Their body is also much cleaner, since they know that they have to take a bath before their examinations. This may seem pretty basic to you, but many women who never worked and who do not have much formal education, are completely unaware of these things.... Moreover whenever these women see a doctor they start to cry and whine about their problems in such an incoherent way that I often fail to understand which problem bothers her the most. However, the women who work, especially the ones who work in big public or private firms, often read a book or magazine and speak on the cell phone while waiting in order to spend that time in a better way. They know how to greet the doctors and nurses properly and list their complaints in a coherent and clear way, so we become more helpful in finding solutions to their complaints, even though they are the usual and typical symptoms as chronic tiredness and nausea."

From my observations during fieldwork, I noticed that the women who worked also picked up the medical terminology quickly and referred to their health problems using that terminology, which further closed the typical gap between doctors and patients to a considerable extent. Besides using a similar terminology, they were also aware that the more they acted as a "strong and independent patient," the more they guaranteed the

label of a “good patient” in the long term. That is probably why the female patients often talked about their work and how they adjusted their work life according to their days of therapy, especially in the Güvercin hospital, where the health care providers often praised them for continuing to work. The health care providers had a completely different attitude towards the “bad patients,” the women who always lived as dependents on other people and who “attract the attention of others by constantly complaining and whining,” as a female doctor at SSK described. For instance, after a breast cancer woman in her sixties complained that she feels so tired after her chemotherapies that she stayed in bed for most of the time, a male doctor at SSK asked her whether she feels too tired “even to cook a meal or two for her husband.” Later on, when that woman went out of the room, he ridiculed her, by saying that she does not do much in life so her tiredness is just because of her boredom and need for constant complaining.

Since the written illness narratives represent “modal patients” in an idealistic and exemplary way, the female breast cancer patients also wrote about the positive aspects of continuing their work while having cancer treatment. Ayten Özer (2006), who owns a well-known bar, writes that she decided to keep on working in her bar during her treatment, despite the efforts of her friends to convince her to quit working, since the job kept her busy and prevented her from procrastinating about her disease: “When I work, I have to decide on fifty different issues per day, so I do not know how the days go by. If I did not work, I would keep thinking about cancer and what I have done wrong to have it.” Similarly, Fatma Babaoğlu (2006), a human resource manager, said that going to work motivated her to go on with her life during her cancer treatment, since she would focus on herself and her body too much if she stayed at home. She also mentions that her

colleagues were very cooperative at that time and bought a special chair for her so that she could work comfortably at her desk.

The cancer patients I interviewed evaluate the preference of health care workers and modal patients for active and productive cancer patients in a more realistic way, since they are more aware of their own physical limitations. They also have a better sense of the dynamics of work life in different sectors, where colleagues may not always be cooperative and helpful towards people with cancer. Therefore, they often experience the dilemma between feeling frustrated and inadequate as patients “who gave up everything that they enjoy during cancer treatment,” as a doctor at SSK said, and forcing themselves to be active and productive often by denying the physical and psychological effects of cancer and cancer treatment. The dilemma creates more tension for the female patients in the age group of 25-55, since, as I noted above, they also struggle against the view that they can easily quit their job and be dependent on other people financially when they became physically weak due to their cancer.

The dilemma becomes a crucial part of the cancer patients’ efforts to cope with their illness at both personal and public levels, since it also includes the patients’ efforts to create a balance between *their own* needs as a person and what the *other people’s* expectations from them. Selma, a 34 year old breast cancer patient who has her own textile firm, expressed this dilemma clearly when she talked about the difficulties that she had while working and having cancer treatment at the same time: “Sometimes, especially on the days when I feel very bad and exhausted, I feel like closing my firm, giving up all my career plans and living with my parents again. As soon as I begin to make such plans I imagine that the people around me would say that I was not as strong as they thought I was, since I compensated from my life considerably in order to fight with cancer”. Then,

I would not feel that I won the battle against cancer, since it would not be a complete victory...I would be healthy, but unhappy since I would depend on my parents in my thirties, and this is something I avoided doing even in my high school years, when I worked on a part-time basis and in every summer. When I think about all these, I change my mind instantly, and remember my decision to keep on working for a very long time no matter how sick I would become. I think I am quite determined on that decision, despite the times I feel very bad... I was always the strongest daughter of my mother and I will always be.” The patients’ efforts to be strong and independent in emotional and physical terms, however, makes it harder for them to acknowledge and express the physical effects of cancer, as we also see in the discussions of other bodily changes.

**III) Problems of Nausea and Changes in Weight:** The patients who undergo chemotherapy and who have cancer in their digestive system often feel nauseated, which affects their weight and everyday life considerably. Seventeen patients complained about having nausea, which may last for a couple of days, after their chemotherapy sessions. They explained that the nausea often accompanied pain and tiredness and made these side effects even more intolerable. Although the chemotherapy often includes a sedative drug against nausea, which some patients found useful, as I have explained above, the doctors in Güvercin said that the effectiveness of this drug depends on the metabolism of the patient. The previous health history and health problems of the patients also affect the intensity of nausea and how to cope with it in psychological physical terms. In the cases of long-term cancer treatment, having nausea becomes chronic for the patients, who try various ways to live with it. For instance, Gülsüm, whose breast cancer treatment had finished a year ago, said that she felt nauseated all the time during her treatment so that

she accepted it as an inevitable part of her life, just like the times where she was pregnant with her son and she felt nauseated because of her pregnancy. Her comparison of her pregnancy and cancer treatment in that respect made her adapt more easily to nausea and feel strange when it was over after her cancer treatment: “My cancer treatment lasted about two years...Then, my doctors told me that there are no more cancerous cells in my body and I am perfectly healthy. A few days later, I was walking around in a park and I suddenly realized that I was not feeling nauseated anymore! I felt happy because that was the first time when it really dawned on me that I do not have cancer anymore, but I also felt a bit strange since nausea, which was such a typical part of my life, was just gone all of a sudden. When I was feeling nauseated during my pregnancy, I kept telling myself that when that nausea will be over I will have my child, and in a way it happened that way when my son was born. However, when my nausea was over after the cancer treatment, I did not have such a drastic change in my life (She laughs). Only I became healthier, of course, being healthy again was a blessing too!”

The persistence of nausea during cancer treatment makes five patients, including Gülsüm, associate nausea with having cancer and cancer treatment, rather than seeing it just as a side-effect of their treatment, and the lack of it also means the lack of, or considerable decrease in, cancerous cells in the patients’ body. Yılmaz, who is also among those five patients, explained that he felt worse during the first three chemotherapies, but afterwards he had less and less nausea after each treatment, since the number of cancerous cells in his body dropped significantly. As for Tülay Sağlam (2005), a journalist who published her breast cancer narrative, said that she associated her nausea so much with the chemotherapies she was having that she felt nauseated as soon as she

entered to the street of the hospital and saw the building before every treatment session, as if she was “conditioned.”

Another journalist, Sibel Kalaycı (2004), who wrote a book about her breast cancer, also talked about how she constantly struggled with nausea, throwing up, tiredness, weight gain, constipation and pimples during the first three chemotherapies she had. However, she was too ashamed to speak about these problems even to her sister, who is a medical doctor, since she worried that she would make her close family members, who were already devastated after her diagnosis, even more upset. She also explained that she did not know that these problems were the “natural side-effects of chemotherapy,” and thought that they were caused by her cancer itself. When she realized that blood was coming to her mouth from her throat one morning after her third chemotherapy, she wrote that she panicked and cried a lot, and that was a turning point for her in terms of sharing her health problems with other people. Kalaycı thought that having nausea was the worst of all those problems, since she could “never totally get rid of it, and she felt anxious about when it would start, how long it would last and how she would cope with it right after each of her chemotherapy. Similar to Gülsüm, Kalaycı also associated her nausea with the nausea that women feel during pregnancy, although she never became pregnant. She talks about how she hated to feel nauseated even before her cancer treatment and how she decided not to have children in order not to suffer from nausea. However, after her chemotherapies, she thought that she had nausea as much as she would feel if she ever had ten children so that her capacity to have nausea in life was already filled, in an ironic way. Her fear from nausea is also connected with the bulimia that she had when she was studying in the university and the psychotherapy that she had in order to overcome that illness.

The patients also have some difficulties in talking about their nausea with health care providers, especially at SSK hospital. In general, the health care providers consider having nausea to be an obvious side effect of cancer treatment, which they can deal with more easily and directly, compared to “less clear” complaints of the patients, such as pain and tiredness. However, they also lack empathy towards the patients who talk about their nausea, because of its frequency among cancer patients. A female doctor in Güvercin told me, it is almost expected that the patients complain about it, and the oncologists often have a list of drugs and other possible solutions, such as changing dietary habits, in order to decrease the patients’ nausea. She said that if the patients have a severe and ongoing nausea, she suggests eating food with bland tastes, such as bread, pasta and potatoes, and eating frequently small portions of light, non-oily food. Four patients from the same hospital said that they found these suggestions useful to a certain extent and that they were happy that the doctors and nurses were concerned about their nausea. In contrast, six patients who were treated at SSK, said that their nausea were “taken for granted” by the health care providers as an essential and typical side effect of their treatment, similar to their complaints about their pain and aches. Ayhan, a lung cancer patient in his thirties, claimed that his doctor at SSK had a sarcastic attitude when he said: “It is good that you have nausea, you should not complain about it, since it actually shows that the drugs, which we are giving you, work efficiently.” Although Ayhan admitted that this might be true, he also said that he expected “a little bit of empathy or concern” from his doctor on this issue.

The patients’ complaining about nausea in an open and public way is also related with their age group and socio-economic background. Out of twelve cancer patients who are in the age group of 25-55, ten patients complained about nausea and how it affected

everyday life, such as the urge of going to the bathroom for throwing up, in detail. In contrast, only seven patients out of twenty-eight patients from the age group of 56-75 complained about nausea, only when I specifically asked about it, and they did not elaborate their complaint. Six patients, four of whom are female, from this age group, explained that it is not appropriate to talk about “such unpleasant issues,” which they can only talk with the people who are close to them, in the cases of emergency. These patients had a middle and upper class, urban background, and they emphasized that the cancer patients, like them, should also mind their manners, even though they go through a physically and psychologically difficult process. For them, this also because of the fact that having nausea is directly connected to throwing up “which is too unpleasant to talk about in public,” in Ayhan’s words and to pregnancy or other womanly issues, such as menopause, which are “private matters,” as Hamiyet said. Three male patients, including Ayhan, also told that they felt awkward when they felt nauseated and that it was hard for them to talk about it to other people for a while, since they associated this feeling with womanhood.

**Weight Changes as a Health Problem:** The dramatic decrease or increase in the cancer patients’ weight is also an issue that the cancer patients associated with nausea and commonly complained about. As I discussed in Chapter 3, having a slim and fit body has become an esthetic norm that is desired especially by upper and middle class urban women in all age groups. Although the cancer patients evaluate the changes in their weight before and after the cancer diagnosis in a different way, these different evaluations also inform each other. Six female cancer patients said that they were often concerned about their weight and were on a diet at different times of their lives before their

diagnosis. That is why they were concerned about their weight changes during their treatment even more than the other patients who “were happy about their weight” in general. Seven female cancer patients complained about gaining weight, and in contrast, one female patient complained about losing weight rapidly during treatment.

According to the popular and medical discourses on cancer, being overweight and a high fat ratio in the body, increases one’s risk of having cancer, since the cancerous cells develop and multiply faster in the fatty tissues. A female doctor in Güvercin explained that most female patients are also concerned about the fluctuations in their weight during their cancer treatment. She added that most cancer patients gain weight during their treatment, because of the side effects of the drugs and they over-eat to gain strength strong in order to fight with cancer. However, depending on the type and phase of cancer, the doctors prescribe different types and doses of drugs and their side effects also depend on the metabolism of cancer patients. She also added that despite the variations of the drugs and their side effects, they encourage the patients to eat healthy instead of over eating, so that they have the strength and energy to cope with cancer and cancer treatment.

The discourse on over eating and being over weight is also reflected in the health care providers’ views and attitudes at Güvercin and SSK, who also use the patients’ weight as criteria to differentiate the good and bad patients. One female doctor at SSK said that two third of the cancer patients at SSK are overweight, and it was rare for a cancer patient who has a fit and slim body, and who apparently takes care of herself or himself, to be diagnosed with cancer at SSK: “I tell some of my patients, especially the elderly female patients with breast cancer, to lose weight by cutting the meat and carbohydrates from their diet and adding fruits and vegetables instead. For most of these

patients, it is hard to change their eating habits that they have for decades, but once in a while we happen to have surprisingly fit and slim patients as well. Those patients are also the patients who regularly visit hospitals, therefore their cancer is diagnosed in the early stages, so their treatment becomes less problematic for them and for us (she laughs)... Their cancer can be related more to genetic or environmental factors, than the life-style factors, so I pity the patients more than the patients who constantly smoke or who never pay attention to what they eat.

Having slim bodies also helps the female patients to be identified as modern and urban in the hospital and in general, since being slim enables them to differentiate themselves from the women of “past times” or villager women. Gülsüm stated that “chubby women were approved of in the old times and in the villages today, since their fatness was a sign of their strength and good health”: “When I was a child in Istanbul in 1940s or, even now in the villages, the men preferred overweight women, because they thought that these women would not get sick as easily as skinny women, and they were better in physical activities in their house or fields. Now, we do not live physical lives in the city, compared to the past times or in the villages, so chubbiness means a risk for health, rather than a sign of being healthy. For example, when I look at women with breast cancer, they are rather chubby and they have big breasts.” Gülsüm, who clearly internalized the medical discourse on this issue, also related her cancer to genetic factors, since both of her aunts and her mother also had breast cancer. Filiz made a similar comment when she talked about the weight that she gained during her cancer treatment, by saying that she looked like a “villager woman,” like her great aunt, who lived in their village and refused to migrate to the city. She said that gaining weight affected her

interactions with the people around her, and people behaved less respectfully towards her in the streets, public busses and hospitals.

Three female patients explained that they viewed their body and weight in a different way after their cancer diagnosis. When Sıdıka, a breast cancer patient in her sixties, learned that she had cancer, she thought that being on a strict diet was probably inappropriate in her age both in biological and social terms. However, she was also happy about her newly slimmed down body, as a result of that diet, even if that diet “might have triggered the cancer gene that she already had.” She said that her female doctor in Güvercin understood her concern about her weight and explained that her treatment may also cause fluctuations in her weight. After that explanation Sıdıka was afraid to gain weight again, since all of her efforts would be in vain if she “would be fat again,” but she became happy when she lost even more *kilos*: “Now, I think my body is in its best shape, I am very happy about it, but both my doctor and my brothers tell me not to lose more weight, since that could made me weaker and affect my immune system. I stopped having a diet, so that I could be strong in order to fight with cancer in physical terms.” Similar to Sıdıka, Sibel Kalaycı (2004), who “always tried to lose weight” since her early teenage years and suffered from bulimia for a while, also states that having cancer and surviving it, made her look at her “weight issue” from a different perspective. She says that she is now afraid of losing weight, instead of gaining, since her rapid loss of weight led her to see a doctor, and that eventually led to her diagnosis with cancer and her long-term cancer treatment. She mentions that she is still “overweight” after her cancer treatment, she tolerates this more than before, since having appetite and being able to eat means that she has survived her battle with cancer and she is still alive and healthy.

Only three male cancer patients complained about the changes in their weight, and when I asked the male patients how they felt about it, they were taken aback, since they also considered it to be a “womanly issue” similar to nausea. They told me that weight changes are mainly about the look of their body, so it is a personal matter, which should not interest other people. Yilmaz said when he talked about gaining weight with his male friends laughed at him, saying that this disease turned him to a woman who is obsessed about her weight. He said that he lost weight rapidly at the beginning of his treatment, when he had two operations and radiotherapies, but he the started to gain weight so fast that he began to be concerned about. However, he also thought that he should not be bothered so much about these ups and downs, unless he becomes “dangerously thin or fat,” especially considering that cancer and cancer treatment may cause much more serious problems, such as loss of hair.

The male health care providers are also less tolerant about the patients’ complaining of weight changes than the female health care providers, especially at SSK, where they have “more important issues to deal with,” as a male doctor said. That male doctor at SSK also explained that because of nausea and pain, most cancer patients feel reluctant to eat and lose weight dramatically over their treatment. However, about a 20% of the patients do not have nausea and feel happy that they still have the appetite, so they eat as much as they can or they have edema because of the treatment, which causes swellings in different parts of their body. That doctor said that these patients become really disappointed, since they thought that all the cancer patients lose weight during their treatment and expect doctors to console them instead of being concerned about the efficacy of their treatment. He thought that it is a “luxury” for the female cancer patients

to be concerned about their weight changes, since there are much more important aspects of cancer and cancer treatment that they have to be concerned about.

Seven cancer patients evaluated the connection between gaining weight and having cancer in a way that differed from the medical discourse. These patients believed that they also accumulate “bad water” (*pis su*) through over eating, which should be replaced with “good” or “clean” water in order for them to be healthy and cancer-free again. The concept of bad water is also informed by the recent news in the media which often cover which type of food contains which type of fat and how that fat affects the body. Media and medical authorities also encourage drinking water regularly to “clean the internal organs,” and most cancer patients follow this advice closely, “so that their bad water will be replaced by the good one” in Sıdıka’s terms. Sıdıka, a breast cancer patient her sixties, said that she followed those news closely when she was on a diet, and that she paid attention not to accumulate too much fat in her body. For her, “bad water” may also turn into fat, when it lays still in one’s body, and thus one has to have a physically active life: “If you put a bucket of water outside and do not touch it for several hours, it will become filthy, leaves and insects will fall in it, and dust in the air will pile up on its surface like a thin layer...Similarly, a still water inside your body may turn into fat, and later on, god forbids, into a tumor, if you do not exercise and keep the water in your body still. You also have to drink a lot of water which will replace the bad water in your body.”

Although the concept of “bad water” is informed by the recent news in the media, it also refers to a popular medical understanding of the body, and it is also used for other health problems, such as swellings, and diseases, such as tuberculosis (bad water accumulated in the lungs) and gout. Four patients also compared the “bad water” in their body to the water in the underground, saying that both are invisible until they are

accumulated too much and cannot be contained. This comparison also refers to the unknown or invisible aspects of diseases, especially of cancer, which is often diagnosed “when it is too late” in Turkey.

The patients also talked about the swellings in their body as the accumulation of “bad water,” where the cancer cells can spread out more easily. They explained that some cysts are also filled with that water, which has the potential to become a solid tumor eventually; therefore those cysts should be taken as soon as possible when they are detected. When I talked about the “bad water” view with the doctors at Güvercin and SSK, they laughed and said that since these patients do not have medical knowledge, they do not understand properly what they read on cancer and what the health care providers try to explain to them. A doctor at SSK said that cysts may be filled with liquid may turn into solid tumors, but that is not because that the “water inside them is bad.”

The patients contrasted the “bad water in their body,” which is so filthy that it does not flow and which keeps accumulating all the cancerous elements in the body, with the “good water,” which flows with the blood, reaches to different parts of their body, and makes them healthier, by cleaning them. The patients argued that the cancer treatment is about replacing the bad water with the good water, and they should help this process by drinking a lot of water, eating a lot of fruits and vegetables, the juice of which contains the “good water,” cooking with extra virgin olive oil, taking showers frequently and going to the thermal or public baths. The doctors explained that the first part of these measures is the rules of eating healthy foods during cancer treatment and in general, and the measures about frequent showers and baths are about strengthening the patients’ immune system by adjusting their level of stress. However, the belief that the cancerous cells reproduce and spread out more quickly in the “bad water” inside the body, helps the

patients to provide an explanation and come into terms with the process of how cancer occurs and develops in their body. The cultural conception of “bad water” inside the body also takes its strength from its resemblance to the discussions of sea and river pollution and their dangers to people’s health, which are important environmental problems in Turkey. It also reminds these patients of the “Chernobyl effect,” where the Turkish rivers carried high levels of radioactivity from the Black Sea to various regions in Anatolia. Both Yılmaz and Selma mentioned that their veins are like polluted rivers because of their tumors, and Arda talked about the tumor in his lung as being an exploded Chernobyl reactor, which pollutes all of his body through the blood in his veins. The patients believed that the bad water is often contained inside the body; therefore it is invisible to lay people, unless they take the necessary medical tests. However, the bad water may come out in the form of swellings when the cancer is developed. This resembles the case of the rivers, “the pollution of which, becomes noticeable for the lay people without any scientific measurement,” as Yılmaz explained.

Popular cultural conceptions of bad water are similar to the other cultural constructions I discuss here, such as *hastalık* and *rahatsızlık*, *bilinçli* and *bilinçsiz* patients, tumor and *kitle*, and the non-medical meanings attributed to infection and epidemics and to the medical operation of “making the blood thicker.” Those conceptions inform the patients’ evaluation of their illness experiences, as well as the interactions between the patients and health care providers. They also shape the Turkish biomedical discourse in a particular way, since the health care providers have to acknowledge these cultural concepts, even if they associate them mostly with the patients’ narratives, except the categories of *bilinçli* and *bilinçsiz* patients.

The common point of these “minor” bodily changes that I discuss in this chapter is that the different perceptions of the patients, people who are close to them, and health care providers, make it difficult for the patients to share how they feel about these changes and to cope with them. The doctors typically interpret the bodily changes that I described as a part of their professional assessment, by saying “yet another case of nausea” or “one more patient with chest pain,” but these are real and crucial problems for the patients, which they have to cope with on a day- to-day basis. Moreover, these changes also affect the patients’ self-esteem, social interactions and dependence on other people in financial, emotional and practical terms. This makes the patients focus more on these changes and try to find a meaningful explanation of how and why they take place both for themselves and the other people. They constitute a major part of cancer experience, as the narratives reveal, even though they are less dramatic than the loss of hair and breast removal, which I will cover in the next chapter.

## Chapter 7

### The “Major” Bodily Changes of Cancer Patients

Towards the end of my fieldwork I thought that I had a good sense of typical illness narratives of Turkish cancer patients, and that nothing could surprise me about what people would tell me, since I had already interviewed many patients from various socio-economic backgrounds. However, when I started to interview Gülfidan, who stayed in the “breast cancer ward” at SSK, I realized that I could still be surprised by the way cancer narratives cover the most public and private issues. When I introduced myself and asked for permission to interview her, Gülfidan, a housewife and a breast cancer patient in her fifties, replied with a question: “Let me ask you one question first, are you married?” Slightly taken aback by the abruptness of the question and trying to figure out how cancer can be possibly related to marriage, I told her no. Then, even more abruptly and surprisingly, she lifted up her nightgown and showed me the scar that was left after her breast removal operation, and she said: “It is good that you are not married, since if you were married you would be just like me.” Why she made that statement on marriage became clear when she explained that her husband was an alcoholic and a gambler who was beating her all the time. She believed that her problems with her husband led to the accumulation of “an enormous sadness and stress,” which eventually turned into cancer in her breast.

As I discussed in Chapter 4, some cancer patients believe that emotional stress is one of major reasons of having cancer, and that factor is also acknowledged among health care providers who argued that stress weakens the immune system. However, Gülfidan’s

case is different from the other cancer patients, since she blamed herself and her “wrong choice of husband,” rather than an external event such as earthquake, for her illness. She said that the cancer accumulated and spread in her body throughout the years she stayed married and suffered from the problems of her marriage, until her body “told” her to stop this “torture.” She added that she was only 17 when she married and she could not have a divorce, since she thought that it would be inappropriate, and that her husband may improve in time.

Gülfidan also argued that marriage “weakens women,” especially when they marry at an earlier age and without having much education like her, and that women should stay single and educate themselves “for a long time” in order to be strong and independent. Even though she thought about having a divorce and living with her great aunt after her cancer treatment, Gülfidan said that her marriage was the mistake of her life, and the scar in her breast will always remind her that it was the cause of her cancer. Her husband visited her twice in the hospital, and his “obvious reluctance” on these visits only strengthened Gülfidan’s decision to have a divorce. Gülfidan’s story indicated that the removal of her breast left not only a physical scar on her body, but also a psychological one, which would always remind her of the problems in her marriage. Cancer patients’ loss of hair and breast removal can be considered major bodily changes which affect body and self image considerably, as well as having a symbolic power on identity on a long term or permanent basis. Although the patients’ hair grows again after chemotherapy, and becomes even thicker and fuller according to the oncologists at Güvercin, and although some patients are able to afford breast reconstruction, the effects of these bodily changes on the patients go beyond the process of cancer treatment. As the story of

Gülfidan indicates, the narrative about major bodily changes helps the patients to re-organize their public and private lives.

The major bodily changes affect the looks of people with cancer and single them out to a large extent in public and private contexts. They are also traumatic for the patients by underlining the difference between them and healthy people, since “healthy people cannot even imagine that they may lose their breast and hair one day, and how all this will affect them afterwards,” in Selma’s words. Those bodily changes remind the patients and the people around them that the patients had to “emigrate to the kingdom of the ill and live there,” as Susan Sontag (1978) described it, during their treatments which may last as long as 3-4 years (Aran, 2004). Nine cancer patients, including Selma, emphasized that breast and hair are such essential parts of their body, without which they did not feel whole or healthy. Breast cancer is the most common form of cancer among Turkish women, and its commonly late diagnosis often leads to breast removal, and again because of the late diagnosis, most Turkish cancer patients undergo chemotherapy after their operations. Having a shaven head is the visual symbol of cancer both in media representations and in society. Despite the similarities between these two major bodily changes, there are also considerable differences between them in terms of how they affect the patients and their significance in public and private realms.

**I) Loss of Hair, Self-Image and Performance:** Losing hair takes place in both male and female patients as a result of high-doses of chemotherapy drugs. Although it is a temporary loss, seven cancer patients described it as the most dramatic result of having cancer and undergoing treatment. They talked about how they were shocked when their hair started to fall out, even if they knew that it would happen, because their doctor had

warned them. There were only four cancer patients who did not talk about this issue at all, and two of them did not experience hair loss because they were receiving low-dose chemotherapy drugs, and one was at the beginning of her cancer treatment. Four women with upper and middle class and urban backgrounds emphasized that losing their hair was more difficult than losing their breast, since the former was more difficult to “hide in public,” in Figen’s words. This is also partly related to the cancer patients’ differentiation between their face and body, which corresponds to the division between public and private spheres. The cancer patients wanted to project a public message that they *still* looked “somewhat healthy,” although they were having cancer treatment, and a healthy-looking face was essential for that purpose. Looking healthy during long-term cancer treatment was crucial for the patients, since it was a part of their effort to be strong and independent. Even before the diagnosis of cancer, the health problems affecting a patient’s face, such as swellings and lesions, were considered more alarming and valid reasons for seeing a doctor. Mehmet said that the first signs of his colon cancer were swellings in his arms and legs, but he did not worry too much about them for several months, since he thought they happened because he over-used his muscles in old age. However, when the same swellings appeared on his face, especially near his eyes, he and his whole family were alarmed, thinking that this might indicate a serious health problem, and his children convinced him to visit a doctor. Mehmet said that he and other people around him realized how bad they looked when the swellings appeared on his face, and he also was afraid that they could eventually affect his vision.

Ten cancer patients said that they felt better when their face looked good and other people told them that, and they tried their best to have a “healthy face,” in Gülsüm’s words. Gülsüm said that her cancer treatment made her face puffy and increased the dark

circles under her eyes. However, as someone “who always does her best to look good,” she did an extensive research and found hypoallergenic make-up items that could be used during cancer treatment, she also learned new make-up techniques to hide “the damages of cancer” in her face. She said that all of these efforts stem from her wish that other people, especially doctors and nurses, tell her that she looked good. She said that a female doctor in Güvercin, who always complemented her on her looks, “just forgot to complement her” one day, and that she felt “devastated”: “That doctor just said hi and how are you to me, and I thought that there was something very wrong in how I looked...I felt so bad that I had to tell all that to a nurse. That nurse just laughed at me and comforted me by saying that I looked just fine and that doctor was too busy at that moment to have a chat with me. After talking to that nurse I felt so relieved and even laughed at myself.” The confirmation of a healthy and “good-looking face” from other people, especially health care providers, was the key issue for many cancer patients.

In accord with the patients’ efforts to have a healthy and good looking face, eight patients considered hair loss to be the most traumatic part of cancer experience, since a “shaven head meant a public scream, which said that it belonged to a cancer patient,” in Gülsüm’s words. Feriha said that her face seemed incomplete to her without her hair, and that really bothered her. Even though “the other people in the streets” did not often notice her “shaven head,” since she wore a headscarf most of the time, she did not like her looks in the mirror, and the idea that her close family members would see her first as someone with cancer. Feriha said that she initially could “hang around with her shaven head” only when people close to her were around, but even then she thought that she was staging a “failed performance.” She argued that when she felt uncomfortable because of a lack of something as essential as her hair, other people also felt tense, even though she did her

best not to show her discomfort, and conversations became far from natural: “There were those, pitied looks to my head, awkward silences, meaningless small talks made just to fill up those silences, and indirect questions asked in a polite way as much as possible about my treatment. One day, in one of those tense moments, my three year old nephew came up to me and asked whether my hair will grow again, and he asked that question bluntly. Everyone was relieved to an extent, and our conversations eventually became somewhat normal. Otherwise they were like those absurd plays, like Beckett’s ‘Waiting for Godot.’ I also blamed myself or my baldness for the absurdity or the failure of those plays, I could easily point out what was missing, although people were terrified to talk about it (She laughs).”

Feriha’s view of failed performance is also similar to Ceylan’s “unusual performance,” where, being a businesswoman in large, private firm, she attended an important meeting “with top-notch formal wear, large earrings and shaven head”: “There were about thirty people in the meeting room when I came five minutes after the meeting started, and I still remember the utter silence that took place when I just showed up at the door. The silence lasted well after I sat down, and everybody, including my boss, was staring at me, with their eyes wide open, since they always saw me with a small hat or an elegant bandanna until that day. Everybody was so shocked and a couple of people may have thought that I am a true eccentric, but I just wanted to show that I was not ashamed of my cancer and that I did not want to hide anything about my illness and treatment. I felt so brave that day, but people’s reactions to me also made me feel a bit weird. It reminded me of some of the operas I have seen in the 1990s at the İstanbul State Opera (How so?) Do you remember when they staged “La Boheme” with women wearing tight jeans instead of puffy skirts, and men looking like members of a street gang? I saw that

opera twice and really liked it then...My looks and performance in that meeting was just like that opera, unusual but also fun and brave. Eventually people at work became used to my shaven head as well, but of course when I was with my family members I wore my bandanna again in order not to scare my nephews and nieces.” Although they use different methods, both Feriha and Ceylan differentiate their “performance” with “shaven heads” from the usual performance of healthy people, and come to terms with this by sincerely admitting it and turning it into a positive aspect, such as emphasizing Ceylan’s “rebellious and creative character.”

The loss of hair not only differentiates the cancer patients from healthy people, but it also disturbs the connection among the generations. Gülsüm talked about how she felt upset when she found lumps of hair in the brush while brushing her hair one morning. She thought that hair is the most fundamental aspect of a women’s beauty, and that her “thick, honey colored hair that everybody complements” also connected her to other women in her family, who “stood out in the crowd of other women thanks to their nice, long and thick hair”: “My grandmother had one long and thick braid, which was partly white and partly light brown...The silver hair, which sparkled in sun, reminded me of the silver cords that the brides have in their hair in their wedding, and that is why I used to think that my grandmother was still young. She taught my mother to brush her hair for ten times every morning and evening in order to have nice hair like hers, and my mother told me to do the same thing when I was a child...When I saw my hair that came off in the brush, I felt that I was losing all those memories, since I would no longer belong to that group of women in my family because of my shaven head. I knew that my hair would fall off and that it would be temporary, but I could not help feeling very upset, because that loss meant a lot for me!”

In order to cope with this traumatic loss, Gülsüm did extensive research about the shops that sold wigs, and after checking the shops several times, she found the perfect wig, which looked exactly like her hair. She said that she was somewhat consoled when many people did not notice that she had lost her hair, because of the similarity of her wig to her real hair. The increase in the number of patients who lose their hair due to chemotherapy has led to the proliferation of “wig shops” in the Tarlabası district of Beyoğlu, which is one of the main centers of the city. Erhan Zülfikar (2004), who has owned and run one of the biggest wig shops in Tarlabası for the last twenty years, said that there were just 3-4 small wig shops in that district until the mid 1990s, and they catered mainly to the “people from the theater companies and movie stars. He explained that they mostly had artificial wigs with unnaturally bright colors, and the production and marketing of those wigs was a marginal industry, “which fed only 20-30 people the most” at that time. However, this changed dramatically in the mid-1990s, when the people from the entertainment sector were replaced by the male and female cancer patients “of all ages and social backgrounds” who are looking for natural looking wigs that are made of real hair. Zülfikar stated that there are about 15 wig shops in the Tarlabası district now, and most of them are large, well-lit and well-organized places with various sections, which replaced shabby-looking, dark workshops where wigs were once produced and sold. The demand for natural hair also led them to work closely with hairdressers in İstanbul, who both sell them “well-cut, long hair” and who advise their customers with cancer to go the wig shop they work with when the customers begin to lose their hair.

The patients also had to develop strategies about what kind of wig to choose and how to “hide or not to hide their shaven head in general,” in Selma’s words. These strategies are informed by their past and present self-image, as well as views on the

acceptable social norms concerning people's looks. Selma mentioned that she always dreamed about having a rebellious image, by losing weight and shaving her head when she was a teenager, and she remembered those dreams bitterly when she saw that her hair was coming out while she was taking shower. She said that by dreaming about something so marginal and weird, she almost "asked to have cancer" or predicted that she would have cancer. She eventually decided to take her loss of hair as an opportunity for trying her new and much-wanted image, "by going around just with her shaven head," like Bahar, the heroine of a popular TV series and movie, *Asmalı Konak* (The Mansion with the Grapevine), who also had cancer. She attended several business meetings without covering her shaven head, and she was well accepted although she was sure that "they all thought that women should have nice and long hair." She added that the fact that she "was young" and had "the appropriate make up and clothes," made her looks "trendy rather than weird" in the textile industry where she worked: "People whom I work with made jokes that I just followed the trend set by the character of Bahar. Of course they did not know that I actually had cancer. However, when I was in my neighborhood or among my close family members, I did not want to upset anyone further, so I wore either a nice bandana or a hat to cover my head. Having a wig seemed to me a deception for myself and other people around me, so I just did not feel like having one, like most of the other cancer patients."

Both Ceylan and Selma dared to go against the common norms of how women should always have nice hair and enjoyed surprising their colleagues by their "uncommon looks" and by refusing to use the deception that is created by the wigs. However, their efforts to present their identity and image as cancer patients, and to let their colleagues face this reality in all of its bluntness, are restricted to the public realm. Both Ceylan and

Selma still had to follow the common social norms about a woman's looks and hide their shaven heads when they were with their family members, friends and neighbors, whom they "care about in emotional terms," in Selma's words. Hiding their shaven heads indicates their concerns for those people's emotions rather than deceiving them by "putting on an unnatural piece of hair, which does not even belong to them," in Ceylan's words. This is another example of how having cancer leads people to differentiate the people who are close to them and the "others," as I discussed in Chapters 4 and 6. However, appearing in public with a shaven head is much more common in the last few years among the female patients who are in the age group of 25-55 in Turkey, and these patients are largely encouraged by the public figures with cancer who did the same thing. These women mostly have professional careers and claim their right to be "as strong and independent as possible" despite their illness. When I asked women in the age group 56-75, most of whom never worked, whether they would go out or visit friends without their wigs, the answers were invariably negative, and ranged from rolling their eyes to "Absolutely not! The male patients are, in general, less concerned about covering their bare heads, and three of them even stated that having a bald head is fashionable these days. However, this does not mean that they do not need to cope with the loss of hair, which affects their social interactions and sense of control over their lives.

**Loss of Hair and Male Patients:** Although having long or healthy looking hair is mostly associated with femininity and female beauty, as Gülsüm mentioned, the loss of hair is also traumatic for the male patients, since they also take it as a sign that they have cancer and they do not want this sign to be visible in public. Loss of hair becomes an issue which isolates them to a large extent and leads them to differentiate the people they

feel close to (or who are in their private domain) and other people, in terms of sharing their cancer experiences and narratives. As I also discussed in Chapter 4, the cancer patients choose when, how and with whom to share their illness experiences, and these choices become strategies that empower them, by giving them a sense of control over the course of their illness. The male patients were more concerned about that differentiation and those choices, in order not to harm their image as the strong “chief of the family,” who takes care of the women and children “in his chieftdom” in every possible way. Both Altan and Yilmaz said that their first reaction to their diagnosis was to gather their wife, their siblings and older children around a table, in order to take the crucial decisions, such as whom to talk to about the diagnosis, and which hospital to choose for treatment. Altan even mentioned that after learning his diagnosis he was “as cold-blooded as an experienced sea captain, who guesses that a big storm is about to come and gathers his crew in order to give them directions about what to do.”

In that context, loss of hair becomes a secret, which the male patients want to share only with the people they feel really close to, since they do not want to share this sign of their weakness and sickness with just anybody and anytime. This concern also affects the choice of hairdresser and creates a special bond with the hair dresser, who almost becomes a family member,” in Abdullah’s words. Abdullah explained that “it really dawned on him” that he had cancer when his hair started to come off towards the end of his first set of chemotherapy in the summer. He felt very depressed and decided to go to his village in Sivas, so that he did not go through this in the city, where “everybody in the street” would look at him and see him as a cancer patient first: “In my second day in the village, I went to my old barber, who used to cut my hair when I was a child and whom I saw as an old uncle, and told him to shave my head. He became surprised and

asked me why I wanted to get rid of all that thick hair, which had not even become white. Then I told him about my cancer and asked him not to tell any other people. He said ‘I am really sorry for you, son’ and he shaved my head very carefully. When I came back to İstanbul, people asked me why I shaved my head, and if I did not feel close enough to them, I just told them that I did it because of the hot weather in summer.” Hair is an essential part of one’s looks and identity for the male cancer patients as well, and loss of hair also damages the self- image and leads them to isolate themselves in their social life, as Altan explained: “The first time I looked at the mirror after my hair was shaved, I almost did not recognize myself. I definitely looked older and sicker. Without my hair, my eyes seemed to become bigger and even more bulging. Therefore, I stopped seeing many people whom I did not want to notice these changes in me and to comment on them, since even I do not like the way I look like...A month ago, my grandson made me buy a tiny sea turtle for him, but being seven years old, he only fed it once or twice, and afterwards he was bored with such a dependent and ugly creature. You see, it is now on my table, since I noticed that nobody was taking care of it, and I took it to my house. I think it is pretty ugly too, but I also feel some sympathy for the creature, since it somewhat looks like me (he laughs). He is bald, has bulging eyes and has a wrinkly face just like mine. We are also a good company for each other, since most days, my daughter and wife are not in the house, and we are left to ourselves.”

**Loss of Hair and the Health Care Providers:** Hair and hair loss are also sensitive issues in the hospital context, and the hair of female health care providers are either very short or in a pony-tail at both Güvercin and SSK hospitals, for practical reasons and also for concerns about the sensitivities of the patients, most of whom had

lost their hair. During their coffee and cigarette breaks at Güvercin, in the recreational room that they share with doctors<sup>41</sup>, a few nurses with long hair, untie it as soon as they enter the room, so that “they do not have a headache,” and they often talk about the difficulties of keeping their hair long in the hospital context. The health care providers also told me either to have my hair cut or to wear it as a pony-tail for the same reasons, and one female doctor at Güvercin explained this rule: “This is not a written rule, but we do not think that it is appropriate to wander around flipping our long hair, since there are so many patients who lose their hair and will be bald for several weeks or even months here. The chief doctor is very sensitive about the issue, and he even warns the female nurses and doctors who often change their hair style not to come to the hospital looking like an actress rather than a health care provider (She laughs). This rule is even stricter at SSK, where a nurse said that the hygiene standards are already really low, because of the crowd of patients and lack of payment for an adequate number of cleaning staff. On top of all that, they cannot afford to have the female health care providers’ hair falling down on the floor and furniture, and adding to the all the other dirt in the hospital.

The hospital is also one of the few public places, where most cancer patients do not have the need to hide their lack of hair, since they are “all in the same boat and have nothing to hide from each other,” in Hamiyet’s words. However, the health care providers at Güvercin notice and talk about the female patients who do not wear anything on their shaven heads outside, and praise their courage and emotional strength. A female doctor at Güvercin described these patients as self-confident and strong enough to publicly acknowledge and display the effects of cancer. She stated that it is easier for her

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<sup>41</sup> Although the recreational room is for all the health care providers, it is mostly used by nurses since the doctors rarely find time to have a break, and prefer to have their coffee and cigarettes after the lunch in the cafeteria upstairs.

and other health care providers to deal with these patients, since they are emotionally ready to face what cancer and cancer treatment will bring to them.

**Loss of Hair and Written Cancer Narratives:** The books on cancer narratives also include how the authors felt when they lost their hair, as well as providing suggestions for other cancer patients on how to cope with that loss. Sibel Kalaycı (2004), a journalist and a breast cancer patient in her thirties, suggests that cancer patients shave their head before their hair falls off, rather than cutting it short, since when her short hair fell off, it took “several days” for her and her sister to clean her hair off of her pillow sheets, hats and furniture in their house. Like Abdullah, Kalaycı also writes about her personal interactions with her hairdresser, who convinced her to have her hair cut short instead of shaving it, saying that he did the same to her daughter, who was also a cancer patient. She confesses that she felt guilty in her next visit to the hairdresser, when she learned that her hairdresser’s teenage daughter had died of cancer, and that she had survived it.

Tülay Sağlam (2005), a breast cancer patient in her thirties and a journalist who specializes in health issues, also cut her hair short instead of shaving it, and did not expect to lose her hair which come as “a fast and radical blow” while she was in the shower, just like Selma. Although a nurse said that her hair would fall off on the eighteenth day of her chemotherapy, she “forgot” that information until she realized that her hair was coming off each time she touched it in the shower. She was so traumatized that she started cry, but only after turning the water on, so that no one heard her voice, in order not to upset her family further. Similar to Gülsüm, Sağlam was also proud of her hair’s beauty, and she saw it as an essential part of womanhood together with her breasts. Together with her

husband and best friend, whom she also shared different processes of her cancer experience, she chose a wig very similar to her hair before she cut it. She admits that she would choose a “crazy wig” very different from her hair if she was buying a wig to have fun, but since that was rather an “emotionally heavy task” for her, she chose a wig, which was made of real hair and which did not “alienate her own face” from her. Her hairdresser who cut her hair short, made jokes and told stories about the unimportance of her hair, and people around Sağlam told her that the short hair looked good on her, but all these efforts did not really comfort her. She thought that the trauma she had while the hairdresser was cutting her hair short, was similar to the trauma that she experienced when she was fifteen years old and a hairdresser cut her hair very short so that she did not catch flea or lice in the boarding school. The “cold walls” of the public hospitals also reminded her of the walls of the dormitory in that boarding school, and that sense of pain, which she experienced while having her hair cut, and having short hair also symbolized the difficult adjustment process first to the boarding school and then to the hospital.

The only male cancer patient who wrote a book on his cancer experience, Kazım Kanat (2003), a lung cancer patient and a sports commentator in his fifties, describes the loss of hair as the “second blow,” which also caused dizziness and confusion in his mind. Again, like Abdullah, he describes how his regular barber “examined” his head and said that “the only solution is shaving” his head, “just as seriously as the doctor who examined his tumor and decided about the treatment.” He says that although he initially had a hard time with his new look, he became used to it, since everybody around him liked it, and said that it provided a “new charisma.” He also writes about how the cancer patients recognize each other from their shaven heads and establish solidarity, which the healthy people fail to understand and share. He gives an example of a nurse with cancer who has

no hair left and who “forgot to take care of herself while taking care of her patients,” as she had said. He and that nurse often smiled at each other and talked about not only cancer, but also literature and football during his stay in the hospital. The authors wrote these books mainly to guide other patients about how to cope with their illness. Shaving or cutting the hair short before losing the hair, confiding to the hairdresser about cancer, finding a wig which resembles the patient’s natural hair, and forming solidarity with other cancer patients with “shaven heads” are all suggestions for other cancer patients on how to cope with hair loss.

**II) Breast Removal and Intimate Interactions:** The removal of cancerous body parts, such as the female patients’ breast, affects their identity and sexuality, as well as their everyday lives and social interactions. The women from different age groups and socio-economic backgrounds react in different ways to these operations, and this influences the way they talk about them. SSK and private hospitals also have different policies about removing breast tumors, depending on the patients’ ability and commitment in continuing their treatment. Metin Aran, who is the chief doctor at Güvercin hospital, explained that at Güvercin they only have units for diagnosis and treatment of cancer and that the doctors suggest a list of hospitals to the patients for the necessary operations. The doctors at Güvercin also have a list of possible surgeons and hospitals both from the private and public sector, and they discuss these options with the patients as well as communicating with the surgeons before and after the operation. Aran said that around 70% of their patients have their operations in private hospitals, where often just the cancerous part of the breast is taken out rather than removing the whole breast, in contrast to SSK, where the whole breast is taken off in most operations.

The SSK doctors think that the patients do not come to the hospital again once they are cancer-free, since their health ceases to be a priority once the doctors have told them they are fine, although the same doctors also emphasize the importance of regular check-ups. In contrast, Aran explained that the doctors in the private hospitals also take into account the patients' psychological condition and esthetic concerns, and prefer the partial removal of the breast in the cases where the cancerous cells are not widespread. The small sample of breast cancer patients I interviewed at SSK and Güvercin also reflected this difference. Five out of eight breast cancer patients at SSK had their whole breast removed, and one of them lost both breasts. In contrast, only three of the female patients in Güvercin had their whole breast removed.

Reconstruction of the breast is not common among the patients I interviewed, and only Lale, a thirty-one year old patient who had chemotherapy in Güvercin, had that operation. She said that it was important for her to have two breasts for her self-esteem, marriage and work life. She explained that she was married only a year ago and she was scared that her husband "will look at other women" if she "was left with one breast": "My husband suffered enough with me because of my cancer. I was diagnosed with it eight months after we married, and he was in the hospital with me almost all the time during my treatment. Both in Güvercin and in the hospital where I had my operation, I kept hearing stories from other female patients about the husbands leaving their wives right after they were diagnosed with breast cancer, thinking that she will die anyway or that she cannot go on with all the duties of a wife with just one breast... Moreover, our plans to have a child are postponed because of my illness and I felt both sad and guilty because of that. Given all that, my husband was very understanding and he stood by me... Therefore, I thought that it would be unfair for him to be married to a women with one breast for so

many years ahead of us...Despite all they say in the media, I also do not think there is anything esthetic or nice about having one breast. I also work in a travel agency, where I always have to be presentable and that also affected my decision.” Two women in Güvercin and one woman at SSK said that they think about having breast reconstruction later, depending on their health and economic situation and, only one of these women was over forty. The other women who do not think of having their breast re-constructed argued that their being “cancer-free” is more important for them and it is, in Hamiyet’s words, “frivolous” for the breast cancer patients to think about the look of their body when their health and lives are at stake. This view is especially common among women who were in the age group 56-75, since “it is not appropriate for a woman of a certain age to prioritize their looks,” as said Feriha.

**Absentee Husbands/Boyfriends: A Real Problem or an Urban Legend?:** In contrast to the loss of hair, most female patients considered breast removal a private and personal issue, which should be dealt with in the first place by themselves and their significant others. Although those women felt reluctant to speak about their sexual life and how their breast removal affected it, five patients at SSK emphasized that they appreciated that the husband did not leave them after their diagnosis. This is related to the lower expectations of women with cancer that their husbands will take care of them. Men with cancer did not express similar fears. The women at SSK and Güvercin said that they did not expect their husbands to deal with the bureaucratic matters in the hospital or accompany them in all of their hospital visits. Most women thought that occasional visits or help from the husbands during the cancer treatment is adequate and qualifies them as good husbands who support their wives during their sickness. The female relatives,

friends and neighbors were the people who often help the patients in the hospital and at home, doing the chores such as cooking and cleaning. Therefore, what is expected the most from the husbands or boyfriends is that they have to “put up” with their partner’s illness and do not quit them, rather than showing active support in emotional and material terms. Lerna said that her illness gradually prevented her from doing all of her wifely duties, and that she even had to sleep in another room since she woke up often at night. Like Lale, she emphasized that her husband is a very good person since he did not quit her, even though her “breast is removed.”

The patients considered breast removal to be “the last drop,” which made the already accumulated problems between partners following cancer diagnosis and treatment more unbearable for the men, who “had no idea of how to take care of patients,” in Feriha’s words. Seven women, six of whom were treated at SSK, argued that their husbands were bothered less because of a change in the routine of the relationship because of cancer and its treatment, since they thought that it would be temporary, and other women helped to keep “their house intact.” In contrast, the husbands expressed great sorrow when their wives lost one breast, and they were even “more upset” than their wives, as Sümbül and Lale said, since they thought that would affect their relationship on a more permanent basis, despite the possibility of breast reconstruction. Lerna and Lale, as well as five other female cancer patients, told me that they heard stories about female cancer patients’ husbands who left them immediately after learning the diagnosis in the hospital, since they did not want to live with a woman with one breast. They told those stories in a highly detailed way as if they had directly witnessed what happened, and they often included dramatic details such as the patients “sinking to a chair in the waiting room and crying for hours after her husband left her.” I was struck by the frequency of these

stories, and I asked the health care providers at SSK and Güvercin about them. They said that they did not personally witness, but had heard, those stories from the other patients. A female doctor at SSK even called these stories “urban legends,” through which women consoled each other and themselves, since they were actually upset about their husbands’ lack of active support, and they could not express their sorrow directly. She also argued that the female patients used those stories in order to justify or rationalize their partners’ reluctance to actively support them, thinking that their partners’ reaction could be much worse. Accordingly, the patients thought that “at least he did not leave me like the husbands or boyfriends in the horrible stories that were told in the hospital” and did not problematize the attitudes of their absentee husbands, as long as they stayed together or married. However, Sedat Özkan (2006), a psychologist who often works with breast cancer patients, points out the need for more active support from the male partners, which may also make a difference in the effectiveness of cancer treatment. Özkan emphasizes that the patients with good and supportive partners cope with cancer more easily, and in contrast, the “lonely patients” could feel even more alone and experience withdrawal from life during their treatment.

**Breast Removal and the Public and Private Aspects of Marriage:** Similar to the Gülfidan’s story on marriage that I told at the beginning of this chapter, the female patients’ efforts in dealing with the estrangement between husbands and wives indicate the private and public acknowledgment of a marriage or togetherness. The private and public evaluations often differ in the case of female patients, because of their efforts to confirm their partners’, albeit limited, support and their togetherness in the public realm, despite the estrangement and serious problems that they experience in their private life.

Six female patients, four of whom were treated at SSK, explained that they experienced problems in their relationship or marriage after their diagnosis, and that these problems became much worse when their breast was removed. The two women who were treated in Güvercin spoke less about those problems, which they tried to solve “mostly by themselves” and shared them with only one or two people, who are really close to them. This was partly because of the boundary that they drew between their private and public lives, and their concerns that “other people” pitied them, thinking they “already lost one breast and may be on the brink of losing their husband,” in Sümbül’s terms. This attitude was quite common among female patients in the age group 56-75 and who were treated at Güvercin, and it was a big contrast to the attitude of women at SSK who were in the same age group, such as Gülfidan, and who openly talked about the problems in their private life. The fact that more women expressed marital or relationship problems due to the removal of their breast at SSK hospital does not necessarily mean that the women at Güvercin experienced less problems in their marriage or relationship. It rather indicates their reluctance to talk about “personal” and “private matters” in public, or in the interview context more specifically. However, the female patients in Güvercin can also ask and negotiate for their partners’ active support more easily than the patients at SSK, thanks to their more advantageous socio-economic background and their internalization of medical views on how the close family members of the patients should support them. Moreover, the fact that many female patients in Güvercin have professional careers, regular wages and economic independence may also help them to be less concerned about a possible divorce or a break-up.

The four women with breast cancer who were in the age group 25-55 and who were treated at SSK were the most vulnerable to the “threat” that their husbands or

boyfriends may leave them, since they also complained that they could hardly live their relationship in a private way. They explained that the men's mothers and female siblings began to interfere more in their relationship, trying to convince their partners to quit them. Mine, a recently married breast cancer patient in her early twenties, said that she even overheard her mother-in-law asking her son whether he really want to stay married to a sick woman, who may die soon or who may stay with one breast all through her life. She argued that her husband seemed not much affected by these questions yet, but she was also very concerned about these "seemingly innocent questions" turning to "constant pressure," which her husband may eventually yield to.

**Male Support for the Female Cancer Patients and the Media:** The media is also concerned about the issue of husbands or boyfriends leaving female breast cancer patients. For instance, several popular newspapers which covered the cancer experience of the actress Açelya Elmas, a breast cancer patient in her twenties, criticized her boyfriend who quit her towards the end of her treatment. Her treatment took place between 2003-2005, and it included several operations where her breast was removed and eventually reconstructed. The headlines emphasized that she won her battle against cancer, but she was still suffering from the emotional trauma of her break up, despite Elmas' statements that she was not angry and did not blame her boyfriend who could not cope with the hardships of the long treatment process. The journalists and doctors who commented on this statement on TV and in newspapers, explained that it was a testament to the emotional strength and endurance of Elmas, and presented her as the "exemplary patient," since she could fight with cancer "all by herself." In contrast, husbands who stood by their wives throughout treatment, such as the café owner, Mehmet Öktem (2006),

were praised as men who showed rare emotional strength. Öktem who married twice and lost both of his wives to breast cancer, and who became an active social worker in a cancer foundation, also described himself as a person who truly understands women and takes their side, “unlike many other Turkish men.”

A similar concern is presented in a dialogue of one of the most popular TV series in 2003, *Bir İstanbul Masalı* (An İstanbul Tale, 2003). The dialogue was between the character, Suzan, who is an unselfish, loving mother of three grown-up children, and her husband, Cemal, who is also a loving, exemplary father and husband. A tumor was detected in Suzan’s breast and the doctor explained that she must have an immediate operation in order to remove the tumor and possibly her breast. The time between diagnosis and operation was described in detail, by focusing of different family members’ and other peoples’ exemplary reactions, such as crying in secret in order not to upset the patient, and making her rest comfortably in her house. In the intimate dialogue between Suzan and Cemal, which took place at night in their bedroom, she asked him in a worried tone whether he would still love her and stay by her side if her breast was removed. To answer her, the husband started a monologue that what he loves the most about her is her inner beauty and her loving and caring spirit. He said that he will keep on loving her, as he loved her the first time they met, no matter what would be the result of the operation. The scene ended when Suzan happily hugged Cemal, and a similar scene was repeated in the hospital before the operation, where Cemal kept holding Suzan’s hand until the last moment, when she was taken to the operation room, saying that he loves her and he will always be by her side. In my research in the Ministry of Health three months after those episodes were shown on TV, I learned that these scenes were suggested to the script writers by the public relation department of the “War Against Cancer” section of the

Ministry, in order to show how a cancer patient should behave and how their family should show their support for the patients. Although these scenes were overly dramatic and emotional compared to the personal interactions that I observed in the hospitals, they were interesting in terms of their emphasis on the “right attitude” of the husband.

**Breast Removal and the Public Realm:** As Gülfidan’s story at the beginning of this chapter indicates, some female cancer patients were comfortable about talking about their breast removal and showing their scar after the operation in public in the hospital. Those women were also more open in discussing how this operation affected their lives and personal interactions in general. They were mostly the SSK patients, who came from a disadvantageous socio-economic background and who belonged to age group 56-75. Those women did not believe that the operation of breast removal was a more intimate or private matter than any other surgical operation, and they were actually relieved that an organ “which had no function left, but making trouble,” in Zarife’s words, was removed from their body. Zarife, a housewife in her fifties, explained that if a tumor would be in her arm, then they might cut her arm off instead of breast, and she could not do anything easily: “Then I would not be able to do any chores in the house and would live as a handicapped person. People would look at me and pity me everywhere I go. Now I do not have one breast, and although I was initially worried about that, I realized that nobody actually notices it in the outside. My husband does not seem to care that much and so I stopped caring as well. I am actually happy about getting rid of that trouble making part of my body (She laughs).” Zarife said that her breasts also did not have a crucial function in her body, since the time when she breastfed her babies was long ago, and that she stopped caring about what happened to them for a long time before the diagnosis.

Gülfidan thought that the removal of her breast actually strengthened her, since by looking at her scar “for many times every day,” she remembered how much her husband made her suffer both physically and emotionally. She said that a doctor pitied her and understood that she could not go home during her treatment, not only because of health and economic conditions, but also because her husband might harm her further. Towards the end of our interview, when I noted that Gülfidan was comfortably speaking about her operation and showing her scar, she said that it was just another operation like the others and there was nothing to be ashamed of, just as Zarife had said. Feriha, who was in the bed right next to her, confirmed what she said, and stated that the prevalence of breast cancer in the society, and its high visibility in the media, had also made it easier to talk about these issues. She added that breast cancer patients should express how they suffer as openly as possible in order for the healthy people hear their voice: “Of course, all the cancer patients have to talk about their condition, so that healthy people would also think about why all these people have this illness and what makes us suffer so much in the hospital. In order to attract the attention of healthy people, especially the politicians, we have to speak as openly as possible, without being ashamed of anything. The people who cause our illness and suffering should be ashamed instead of us.”

In contrast, the breast cancer patients who were in the age group 25-55, and who constituted a minority among other breast cancer patients were reluctant to talk about their breast removal in public. This was true both for the patients in both SSK and Güvercin, and their reluctance was related to the feeling of “unfairness” of having breast cancer and losing one breast at a “relatively young age.” Lale, a thirty-one years old breast cancer patient, mentioned that most breast cancer patients she knew were in the age group of her mother, and that even those women pitied her because she lost her breast at

such a young age. She said the general reactions of people had aggravated her feeling that what happened to her was just unfair: “First I was telling my close friends and colleagues that one of my breasts was removed as a part of my cancer treatment, but they kept saying with a shocked look on their face, ‘Oh! But you are so young, how come you had such a bad type of cancer?’ I was patiently answering them, by explaining that the number of young people with cancer has increased lately in Turkey, as I had read in the newspapers... However, I eventually ran out of patience and began to question why I kept trying to justify my illness and treatment to the other people. It became harder for me to talk about my breast removal because of those reactions, which made me depressed and confused at the same time... Then at one point, I decided not to talk about my operation that much, and I thought ‘I have cancer and my breast is removed’ this is not anybody’s business, but mine! So, when people ask me specific questions about my health condition now, I just say ‘yes, there was a tumor in my breast and that was removed’ I do not say anything more.”

Figen, a patient in her thirties who was having her treatment at SSK, also said that the removal of the breast is a private and personal matter, which should only be her concern or that of her future boyfriend or husband. She also noted that she only spoke about the operation and how it affected her to her close family members and friends, and that she told those people to keep what she talked about as their secret. She said that most of her neighbors, some distant relatives and her parents’ friends eagerly asked about the specific and graphic details about her operation and treatment, thinking that anything can be material for gossiping. She said that she was rather astonished when she witnessed their “unlimited curiosity for gory details” and saw “their wide-opened eyes and eager expression on their face, as if they were listening her talking about a horror movie that

they just saw.” Like Lale, Figen said that those reactions taught her to keep most of what happened to her to herself, and to talk about those issues only with people who genuinely cared about her.

The women who talked about their breast removal most reluctantly were the patients who were treated at Güvercin and who were in the age group of 56-75, in contrast to the female patients at SSK who were in the same age group. These women were mainly from upper and middle classes and most of them had never worked in their lives. Therefore, they spent most of their “rather protected lives,” in Sıdıka’s terms, among a small number of family members and friends, and they had a sharp division between their public and private worlds. During the interviews with those women, I realized that they felt rather uneasy in talking about personal or private matters with me, unless I found a common point of view or a specific topic that they liked to discuss, such as their esthetic concerns. Unlike the views of women in their age group at SSK mentioned above, the female patients at Güvercin thought that anything that took place in their breast is directly connected to womanhood and sexuality, and it is hard for them to talk about these issues, even with the people they feel close to. These women were also afraid that other people would think that they were being superficial if they talked about such personal details when their lives were at stake, as I also mentioned above. Given all this reluctance to talk about the issues around breast removal, the extreme openness of women in the age group of 56-75, who were treated at SSK hospital, was refreshingly exceptional, and was also related to the fact they had “nothing to hide or lose” in Gülfidan’s words. Those women also expressed their helplessness and their problems because of the lack of people who listened to them and really cared for their suffering. In

that context, four of them told me that they were glad that I was asking questions about their disease and treatment, and more importantly, listening to how much they suffered.

**Breast Removal and the Medical Realm:** Health care providers in Güvercin and SSK were also aware of the psychological and social problems that women experience when their breast was removed. However, with the exception of two doctors and a nurse in Güvercin, they claimed that they did not have much time to discuss these problems, since their main purpose is clearing the cancerous cells off the patients' body. Accordingly, they thought that it is inappropriate for cancer patients to dwell too much on problems that are not directly related to the "battle against cancer," such as their worries about the removal of their breast. A male doctor at SSK said that when the tests and biopsy show that there is a tumor in the patients' breast then their "race against time" starts and even a week of delay between the diagnosis and operation can cause the rapid spread of cancer: "I wish Turkey was a much more developed country and each cancer patient could solve their psychological problems with a professional counselor in the hospitals. However, this is not possible for our hospitals, except the few private and very expensive ones in İstanbul. Especially in the state hospitals doctors have a very limited time for each patient, and we want to cover so many issues that are vital for the battle with cancer in that time. Unfortunately, we cannot really tell patients about how to cope with the loss of a breast specifically and we also cannot guarantee that a patient's breast would not be removed, since it is a decision we make during the operation in most cases. Therefore, the patients think that we are heartless doctors who do not care about their patients, but this is unfair since we do our best to heal them medically, if not psychologically." The health care providers, especially the ones at SSK also pointed to

their difficulties in respecting the patients' privacy in the hospital context, where "everything happens in public in that crowd" and the doctors know "every little detail" about their patients' body.

However, the patients still blame the doctors "who really care about them or how they feel" in Gülsüm's words. Gülsüm thought that the doctors, especially the male ones, are "totally insensitive" about how breast removal may affect the patients, and she gave an example where a male doctor used her as a "guinea pig" in her words: "Right after my operation at SSK, the doctor who removed my breast told me to come to his private office in order to check the results of my operation. So, I went there just five days after my operation, all exhausted and shaken. I still had the bandages and could hardly move... When I lay down on the examination bed with only a little paper dress on me, that doctor told me to wait for a while and he disappeared, leaving me in that cold and empty room. When he came ten minutes later, he was accompanied by five medical students!!! There was only one woman among them and they all looked like they did not shower for days...The doctor talked about me, by saying "our case," "our patient," and did not even introduce those students to me...I did not even know whether they were students or interns, or what exactly they were doing there. But the worst thing happened when he told me to undress, removed my bandages and showed my scar to these students, some of whom also touched my skin with their dirty fingernails and I felt like throwing up...I felt both angry and embarrassed, since I must have looked horrible with my scar, pale and sick body. I would not want anybody see me like this, let alone perfect strangers! (Did you tell your doctor anything about your feelings that time?) I did not want to embarrass my doctor in front of his students, but after their discussion about my operation, I told him that his behavior was inappropriate and that he should have asked for my approval

before inviting all those students in. He just laughed and told me that things do not work like that in science and medical education. He went on and on about how much the students profit in seeing “the neat operation that he had on *my body*, so I gave up arguing with him. This happened two years ago, but when I remember it, I still feel angry as if it happened yesterday.”

Gülsüm was a typical patient among the women who were in the age group of 56-75 and who were treated in Güvercin, in terms of having a clear differentiation between public and private issues and reluctance to talk about her breast removal “in public.” Nevertheless, I had one of my longest and most successful interviews with her, because she liked “my asking permission, my sensitive approach, and my questions on her esthetic concerns, which could rarely be found in a hospital context,” and which gradually made her feel familiar with me. Gülsüm contrasted my behavior with that of the doctor “who let his students touch her” and who “violated her privacy so shockingly.” What happened to Gülsüm was not an isolated case, although the other cases of “educational sessions” I heard or witnessed, took place in the hospital context, so they included such routine procedures as asking the patients’ permission a few minutes before the session. However, the patients “felt obliged to say yes to the people who try to cure them” in Selma’s words, although they also “hoped that they could have some empathy and sensitivity during those sessions.”

**Loss of Breast and Written Cancer Narratives:** In the books on their cancer experiences, the female patients, most of whom are in their thirties and who had their treatment in various state and private hospitals, express their views and emotions about their breast removal more openly than the female patients I interviewed. They also relate

this issue to their concerns about self-image and sexuality more directly in their writing. This is possibly because of their concern about being “model patients” who are not afraid of facing their problems related to their illness, and “modern women” who are not ashamed of writing about their sexuality. They also emphasize the “unfairness of” having their breast removed at such a young age, similar to patients who were in their twenties and thirties when I interviewed them. Compared to my interviews with breast cancer patients, the written narratives include an open resistance to the medical authorities’ prognosis of the need for breast removal. The resistance stems from the patients’ dilemma between their reluctance of losing an essential part of their body and obeying what their medical cancer treatment demands. Tülay Sağlam (2005) describes how she behaved “inappropriately for the first time in her life of 34 years,” in arguing against her doctor who told her that she had to have an operation immediately, as a result of which “at least one third of her breast” will be removed. She writes that all of her life she has behaved in accord with what people wanted and expected of her, until her confrontation with her doctor where she felt “an urge” to refuse her treatment and “choose the easy way” by escaping from it. She admits that she was behaving “like a naughty and stubborn little girl,” and her behavior was a part of the typical denial stage of psychological trauma. She describes her doctor’s efforts to convince her to have the operation by telling her that she is a “conscientious” person and that she has to accept that “they have to clean that region,” and also her constant refusal of the removal of her breast despite the doctor’s efforts. As a result, the doctor gave her a permission to think about the operation for one day, and he suggested that she spent the day by walking outside in the fresh air.

Sağlam writes about having tidal waves in her spiritual well-being that day because of her fears of losing her breast and her hair: “I touch my hair, which will fall

soon, and with the same automatic gesture, I touch and cup my right breast. I know that it will be removed. My feelings are too hard to cope with. Hair and breast are two of the most important symbols of a woman. When one thinks about losing both of the symbols of her female identity, her femininity dominates her identity as a person. You forget about the health dimension and focus on the physical one, the destruction of your body image, the possibility of not being liked anymore and feeling reduced and inadequate.... These feelings are too hard to cope with.” Sađlam also writes that she wanted to be alone, although her husband tries to comfort her during that process of dealing with her thoughts, similar to the other women in her age group and socio-economic position who do not want to lose their “strength and independence” while struggling with cancer.

Unlike Sađlam, Melda Irmakkesen (2004), a writer in her thirties, believes that losing one breast does not mean the end of womanhood. Taking a feminist approach, Irmakkesen argues that it is the woman who owns her body and she can like it in whatever shape it is. For her, if women like their own bodies, it will make it easier for other people to like and accept these women as well. She also criticizes the women who try to solve their biggest psychological problems about breast removal by themselves, rather than sharing them with their partners. Irmakkesen notes that she realized how important her breasts were for her life when she lost one “in the operation bed.” She describes how people kept complementing on her breasts before she was diagnosed with cancer, and how losing one of them affected her self-confidence, intimate relations and her dress style. She questions her initially negative attitude that led to her blaming her lack of one breast for the unhappy relationships she had after her operation, and she now dedicates herself to work hard so that she does not have time to remember the good times she had in the past.

Unlike the women I interviewed, through her book, Irmakkesen confronts her ex-boyfriend who left her during her cancer treatment, “probably because of her lack of one breast.” She expresses her need to scream as loud as possible: “I am much more than just a breast!” so that her ex-boyfriend and the other people who “branded her as sick” forever, would understand how strong she is. Her struggle with the removal also includes an awakening or “re-birth” in her terms, where she has to discover a new life, where she appreciates all the good things in life which she took for granted before. Her “re-birth” also includes her decision to fully benefit from every moment in life and to be productive and open-minded as much as possible. She finally thanks her breast, which was removed, for bringing out a new version of her. In accord with her new self and as a part of the her efforts to challenge the people who see her as “inadequate,” Irmakkesen also talks about a project of photo exhibitions, which she initiated and which proves that “the women with one breast are still beautiful and attractive.”

Irmakkesen’s view that the women should like and accept their bodies, even after they lose one of their breasts, was also advocated in the first written cancer narrative by the anthropologist Nevval Sevindi (2001), who points out the psychological difficulties for women who lose their hair and breast, “their most feminine symbols.” Like Sağlam, only a part of Sevindi’s breast was removed “as a result of her negotiations with her doctor,” where she said that he should remove her breast only if he believed that the cancerous tissues there could cause her death eventually. However, she argues that women who lost their breast can easily have it reconstructed thanks to the new medical technology and advances in esthetic surgery, or they can join the brave “army of Amazons,” which consists of the women with one breast as a result of cancer treatment. Subscribing to a feminist fantasy, Sevindi argues that these women are the modern

version of tribal women, who lived in the Amazon forests and who have cut one of their breasts in order to become a good fighter. She describes breast cancer as a direct and long-term attack against womanhood, “because of the loss of breast, through which women nursed or dreamed to nurse their babies,” and the side effects such as gaining weight because of hormonal imbalance and loss of sexual desire during chemotherapy. Even after the treatment, the attack against womanhood persists through the concerns about having ovarian cancer as a result of metastasis. Moreover, she also argues that one woman’s breast cancer affects the other women in the next generations, because of “the risk of the cancer patients’ daughters having the same illness.” In echoing the fears of some of the women I interviewed, Sevindi talks about how “in Anatolia” the women relatives of a breast cancer patient’s husband, especially his mother, pressure him to divorce his sick wife and remarry by saying that “She is not a woman anymore.” As a result the men do not even think about challenging this stereotype, have a quick divorce and remarry “as if they won the lottery.” In contrast, she suggests that men should be sensitive and thoughtful for their breast cancer wives and work on having a new and deeper understanding of sexuality with their wives. Her words, “in Anatolia,” connote the cultural and geographical distinction between Anatolia and Istanbul, which roughly corresponds to the distinction between primitive, rural and modern, urban Turkey, as I discussed in Chapter 5. By specifying that the men leave their wives who have lost their breast under the influence of their female realities “in Anatolia,” Sevindi takes a further distance from this problem, which seemingly does not exist in the modern parts of Turkey.

Like Sevindi, Esin Özbek (2006), a 45- year- old accountant in a private hospital in Ankara, also negotiated with her doctor about the treatment plan that he suggested. Accordingly her breast was removed with an operation that took place a week later than

the first one, which was only a biopsy, so that she got used to the idea of losing her breast. This notion of negotiation about breast removal, which only takes place in these two narratives, suggest that both Sevindi and Özbek have more egalitarian interactions with their patients, compared to the other patients, possibly because of their professional career and socio-economic status. Moreover, besides their advantageous background, the early diagnosis of their cancer and the fact that Özbek is a part of the “medical world” qualify them as “conscientious patients,” whom the doctors can trust fully in terms following the medical rules in general. Unlike most patients, Özbek openly criticized the terms that his doctor used when describing the operation that she would have. For instance, she describes her anger against her doctor who said that he would get rid of the cancerous cells in her breast until he reached to the “clean tissues,” since she did not like the word scratch and how it is used for her body. Özbek also thought that she was too young to have her breast removed, similar to the other patients in the age group of 25-55. After learning the diagnosis, “which altered her life plans radically,” she wanted to be alone and kept walking in streets, as did Sağlam, and cried for a couple of days.

The younger the patients the more they are concerned about their loss of breast, especially in terms of its affect on their womanhood. Asiye Saklım (2006), a 26-year-old journalist who works for a private television channel, admits that she is having a hard time in coping with her loss of breast. She mentions that she is still ashamed of her look to the extent that she cannot look at herself in the mirror, and the reactions of other people around her also affected her self-image, like the other women I interviewed “who were too young to have cancer.” She says that everybody around her pitied her by saying that: “She is a very young girl and she is not married, and now her breast is gone,” and, as a result, she thought that she had lost her womanhood: “For me, breast is equal to woman,

so what happens if I have a child in the future? I am a woman who lacks one of her breasts, and that is a very hard reality to cope with.” However, she also thinks that surviving cancer is more important than losing one of her breasts, and she even told her doctors that they should remove both of her breasts if her survival depends on that. This attitude can be contrasted to the negotiations with the doctors on the partial removal of the breast, as we saw in the accounts of Özbek and Sevindi. This full compliance with medical treatment also stems from a sense of guilt for Saklım, since she “failed to have regular check-ups” although she was told by her doctors that she has the risk of having breast cancer.

When the patients are afraid of having cancer, but fully believe that modern medicine is the ultimate solution for fighting against the disease, they can make radical decisions such as was made by Violet Aroyo (2006) a 45-year-old former head nurse and a current manager of a drug company. When a small tumor was detected in one of her breasts, Aroyo asked for the removal of her breasts, her uterus and ovaries in order to prevent a possible spread or recurrence of cancer. The fact that most women in her family had breast cancer and her mother died because of it influenced her decision, which she thought to be a rare but a right one. The operations also led her to work as a volunteer to raise consciousness about breast cancer and the importance of early diagnosis. She is now the coordinator of the “Turkish Breast Foundation” which provides educational support and psychological and economic help for breast cancer patients. Aroyo criticizes the breast cancer patients’ common concern about their personal life after the removal of their breast: “Many women think: “now I am left with one breast, my husband will leave me or I will not have a boyfriend anymore, but so many other, perfectly healthy, women with two breasts are often dumped too.” She argues that women

with breast cancer should not be afraid of fighting against those challenges, and if their husband or boyfriend leaves them because of their breast removal, it means that there was already a crucial problem in their relationship *before* these women had cancer. Aroyo, who is married and has two children, also offers advice on how to talk openly and honestly about “their mom’s breast removal” with children. She says that she now has prosthesis breasts, which prevent her from feeling ashamed that others would see that her breasts have been removed. She also advocates for the main insurance organizations to cover the operations of breast reconstruction, since she defines breast reconstruction as an essential need for the women who lost their breast(s), rather than being a cosmetic luxury.

The bodily changes I described in this chapter are most commonly associated with having cancer and undergoing cancer treatment, and the biggest fears of cancer patients. These changes are the “life and death issues” in Selma’s terms, which bother the cancer patients the most, since they affect their self-image, self-confidence, social and personal interactions, as well as leading them to revise how they view their body, life and death. Those changes lead people with cancer to see themselves as cancer patients first, independent of their socio-economic background, and help them to support each other “no matter where they come from” in Yilmaz’s terms, at least on a temporary basis during their cancer treatment. However, the patients differ from each other in accord with their socio-economic background, in terms of how these changes affect them and how and with whom they share their views on these changes. A major issue for most patients concerns bodily changes, and the patients have only a few people who are really close to them with whom they can talk about those losses. Most patients also never receive professional psychological help, and the health care providers rarely help the patients and their families in coping with those losses. The absence of such outside help makes “their

world much smaller” in Altan’s words, and most of them turn to themselves in finding the resources to cope with those losses and finding a new meaning and wisdom in order to balance their lives.

## Chapter 8

### Death, Survival and a New Wisdom for a New Life

Death is nothing but waste in the production of life; a useless leftover, the total stranger in the semiotically rich, busy, confident world of adroit and ingenious actors. Death is *the Other* of modern life.

Zygmunt Bauman (1992)

As the quote above indicates, death became an offensively meaningless event in the modern world, so that having a lethal illness and the possibility of dying of that illness became something to hide even from the patients themselves (Sontag, 1978, Bauman, 1992). In modern times, where being healthy, fit, young looking and productive, and continuously spending an effort to be as such are praised, death is seen as the ultimate end, which indicates the futility of those efforts. Bauman (1992) describes death as the “absolute nothing,” which resists any attempt to be perceived, visualized and represented. However, he also notes that the impact of death is most powerful when we manage to live as if there is no death for us, or death does not matter to us, and “when we are not put off or vexed by the thoughts of the ultimate futility of life.” Bauman perceives such a life, life forgetful of death and ultimate purposelessness brought by it, as a “formidable human achievement,” and argues that all the social organizations and human culture cooperate to make this achievement possible. Those views explain the “modern denial of death,” in Susan Sontag’s (1978) words, which corresponds to the general reluctance in thinking

and talking about one's own death, or the death of the people who are close. That reluctance is particularly true for most cancer patients, since, having a lethal illness, it is much more difficult for them to live as if they are immortal or that death does not matter to them.

Despite the general reluctance of talking and thinking about death in modern societies, anthropologists have often studied death and dying "as a site for examining the making and unmaking of persons and relationships, social and corporeal bodies, and life itself" (Kaufman & Morgan, 2005). The cancer patients I interviewed and those who wrote about their illness experience also had to face the idea of death and the fact that they may die sooner than they thought because of their illness. Their reaction to the idea of dying of cancer and how that idea changed themselves and their lives is informed by the social and medical conceptions of cancer, as well as the patients' individual characteristics.

The patients' and health care providers' conceptions of death and dying often challenge Bauman's arguments that death as "the absolute nothing" that resists any meaning, as I discuss in this chapter. Bauman views death as a rather abstract concept, rather than focusing on how people face the ideas of death and dying, and he assumes that there is a clear boundary between life and death in conceptual terms. However, especially in the case of cancer patients, the patients' thoughts about death and dying become a crucial part of their everyday life and social interactions and help them to generate new meanings for their lives. Bauman's arguments, like the arguments of most social scientists I cite in this chapter, are derived from contemporary Western societies, because of the lack of studies on the conceptions of death and dying in modern Turkey. Therefore, those arguments are not always valid for the Turkish culture, where illness and death are

considered to be “family matters” which indicates the boundary between people who are close and “the others.”

As noted earlier, cancer is still commonly associated with death in Turkey, and the cancer patients’ narratives include different responses to that association. Güvercin and SSK hospitals have also strict policies about not using the words “death” and “cancer” unless “it is hundred percent necessary,” which also furthers the taboo around those words. Those policies are related to the fact that deaths due to cancer are closely associated with the failure of health care providers and the “irresponsible behaviors” of “problematic patients.” The cancer patients’ responses to the idea of death are informed by their age, health condition, illness experiences, socio-economic background and religious views. They relate death and dying to the bodily changes brought about by cancer, and evaluate death as the ultimate bodily change, which also has social, psychological and philosophical characteristics. The idea of dying of cancer makes the cancer patients draw certain boundaries between the private and public parts of their lives, and to separate people who are close to them from the other people around them. In that sense, having cancer and dying naturally follow each other, since dying of cancer further differentiates the cancer patients from the other, healthy people.

**Death According to the Health Care Providers:** The patients’ views about the association between cancer and death are informed by the health care providers’ policy of not mentioning the word “death” in the hospital. When I asked for permission to conduct fieldwork at SSK and Güvercin hospitals, the doctors and nurses wanted to make sure that I would never use the words cancer and death, unless the patients use them, as I noted earlier. The doctors and nurses in both hospitals often reminded me of those two rules

during the first weeks of my fieldwork, and a doctor at SSK explained that those are the general rules in any oncology clinic in Turkey: “I hope you do not take these rules personally and realize that we obey them too. We never say the words cancer and death, unless we realize that the patients themselves use them quite often, since we do not want to remind them of their illness and the possibility of they may not always be cured. Moreover, some of the patients are better off without knowing what illness they have, such as the ones who are very old and have terminal cancer, and in those cases we speak about illness to their children who take care of them...As you know, many people think they will die as soon as they learn that they have cancer, since there is a common association between cancer and death in this society, despite the success we have in treating many cancer patients. Therefore, no matter what happens, we want to give the impression to all of our patients that they will survive this illness and that all the health care providers do their best. This is the least we can do, since we do not have much psychological counseling at SSK, and if the patients hear anyone, especially a health care provider or a researcher from the outside, just like you, saying the word cancer or death, they would be highly demoralized.”

I noticed the application of those rules in my earlier visits to SSK and Güvercin, even in the conversations among the health care providers in the doctors’ offices, where there were no patients who could not hear them. In those conversations, doctors and nurses often talk about their patients, and if they talked about a patient who died of cancer, they lowered their voices and said “s/he became x,” instead of “s/he died,” and changed the subject as quickly as possible. The use of that medical euphemism also helped the health care providers to take a distance from the topic of death, “which upsets them both as a health care provider and as a person,” as one doctor at SSK told me. He also

explained that even though the health care providers are more acquainted with the idea of death, since they see dead or dying people more often than other people, but that he also added that their acquaintance with dying people and the idea of death does not necessarily mean that they cope with “all that more easily in emotional terms” than the other people. “We just learn how to delay or repress our emotions temporarily and focus on what should be done, such as following the medical procedures and talking to the family members, but of course all of that does not prevent us from being sad afterwards. Sometimes we become personally familiar with the patients who come regularly. We learn so much about them and their lives, and in those cases, it becomes even more difficult for us to cope with their death...Moreover, as a doctor, you also question yourself and your treatment, by asking whether you could actually save the patient, which most of the time is impossible anyway.” As this quote also indicates, this doctor tried to differentiate his professional identity from his patients’ personal and emotional attitude towards the death, and he explained that all the doctors learned to behave like this when they study medicine and in their earlier years of practice. However, that is an effort which is more likely to be unsuccessful at Güvercin hospital, where more patients have personal ties with the doctors. Moreover, patients whose cancer is in advanced stages suffer so much from physical and psychological problems, and have very few people to share those problems with, so it is hard for the doctors to keep their interactions with them at a strictly professional level.

Zygmunt Bauman (1992) explains how the doctors who fight mortal diseases “gallantly and skillfully” see this fight as personal. Depending on the result of the fight, they either rejoice in their victory when “advancing death has been stopped in its tracks and pushed back,” or feel personally defeated when they lose the battle against the

disease. Bauman notes that losing the battle “may stain the reputation of an individual doctor,” but he also adds that “the condemnation of an individual practitioner only reinforces the authority of the art.” According to Bauman, doctors were usually blamed in such cases, since they did not use all the available medical “tools and procedures,” and because of the general belief that “conquest of no disease is in principle impossible” for the modern medicine. As the doctor’s quote in the previous paragraph indicates, the doctors at SSK and Güvercin also feel personally responsible when *their patient* dies. However they also believe that they share this responsibility with the patients as well. Their predictions of which patients will die and which ones will survive are in accord with their distinction between good and bad patients, which I discussed in Chapter 1.

**“Good” and “Bad” Patients, and Death:** A doctor at SSK explained that he began to figure out which patients would survive cancer by observing those “doing their best to be cured” independent of their health condition, and which ones “just prepare themselves to die right after they were diagnosed with cancer.” Accordingly, the first type of “conscientious” patient always has a firm belief that they will be cured, and they adjust their life in order to make their treatment more effective: “I have patients who start to eat healthy and quit smoking right after their diagnosis. They cooperate fully with us, because they know that we, as doctors, do our best to cure their cancer. They are also the ones who start to make research on cancer and cancer treatment, and come to us with intelligent questions on those issues.” In contrast, he gives examples from the patients who give up their hopes “too early,” because they are frightened too much by their illness: “These are the patients who do not even quit smoking while having cancer treatment, since they think they will die of cancer anyway... There are also some patients who do not

care about their health, and ignore the typical symptoms of breast cancer, for example, although the media almost screams about those symptoms. I get mad when I ask a patient how long she has felt that lump in her breast, and she says ‘oh for the last three months’!! They say that they did not have time to visit a doctor, but they do not understand that *their lives* are at stake.” This argument also indicates the health care providers’ categorization of compliant and non-compliant patients which I discussed in Chapters 2 and 7.

The view that modern individuals who should do their best to keep death at bay by battling illnesses and other threats to life stems from the idea that one can have a certain degree of control over mortality by having a healthy life style and fully complying with modern medical practices. One cannot deny that he or she is mortal, but one can delay his or her own death by fighting the common causes of death (Bauman 1992; Lock, 2002). Bauman (1992) explains how finding a particular cause for each particular death is essential in modern medicine and in general, since a person is not expected to die *just* out of mortality. Accordingly, “many deaths from disease often have human intentionality-conscious and unconscious acts as a part of the cause.” In order to delay that inevitable end, modern medicine suggests people adopting such strategies as exercising, eating correctly, having regular check-ups and taking vitamins. Those strategies shape the everyday life of individuals who internalize them, and they require a regular collection of information about the major illnesses in one’s environment and how they can be prevented or cured. These strategies also help “healthy people” to see being healthy as a virtue and a means to salvation (Conrad, 1994). Therefore, the cultivation of health and avoiding death as much as possible become a matter of individual responsibility, according to modern medicine, where, according to Margaret Lock (2002), “the social

and political origins of inequality, illness, distress, and early mortality are deleted from view.” Similarly, the health care providers at Güvercin and SSK hospitals believe that their patients should prioritize their health over other concerns, and fail to empathize with the patients who do not have regular check-ups and who cannot continue their treatment, saying they do not have enough time or money. Anthropologists of health and illness criticized the medical categorization of compliant and non-compliant patients along these lines, and argued that certain external factors, such as not having a health insurance, lack of time and money, may prevent sick people visiting a hospital, even if they believe in modern sciences and medicine (Baer et al., 1997).

According to a doctor at SSK, all the doctors in the oncology clinic are tired of hearing “hundreds of excuses” about why they did visit hospital earlier, such as they could not leave their children or grandchildren they take care of at home, and how their bosses do not allow them to take a break. She also mentioned that the health care providers become skeptical about those excuses and think that those patients do not really pay adequate attention to their health and do not care enough about “such a life and death matter.” She also explained that although some of those excuses can be valid to a certain extent, they do not always blame the patients for coming to the hospital “too late,” especially if they are in a really desperate condition: “Sometimes people who have no one at home, or no money at all come to this clinic, and their condition is very bad as well, and often they are not aware of that either. Then we would not interrogate those people about why they did not visit a doctor before and do our best to help them. We even collect money among us to give to them. However, those cases are rare and we do our best to help those patients without other patients’ knowledge, so that they would not abuse this situation.” That informal help system is only activated in the exceptional cases. In the

Turkish context, the urban, middle and upper classes are most concerned about adopting a healthy life style by exercising regularly, having regular check-ups and taking vitamins, and they can afford their time and money to achieve it. The doctors, living in the same society with their patients, also know that only *some* of their patients can afford to observe such health practices. However, they also expect *all* of their patients to be aware of the major causes of cancer, and whether they are in any of the “risk groups,” and to take the necessary precautions, since cancer is a matter of “life and death.”

Zygmunt Bauman (1992) also argues that the “self-care policy of survival construes death as an individual event,” and makes each death a private and lonely experience. Therefore, it increases the people’s agony about the idea of death, especially in the case of Turkish cancer patients, who can only share this agony with the people who are close to them. However, this argument does not apply to Turkish public figures who published their illness narratives, and who emphasized their gratitude towards the “crowds” of fans who were always with them during their treatment. The agony of cancer patients is also fed by the fact that they do not know whether or when they will die of cancer. The doctors at SSK and Güvercin avoid predicting how many months or years that the patients have left and sharing those predictions with the patients and their families, since a doctor at Güvercin explained that the development of the disease can be altered by the patients’ individual attitude towards having cancer and the social and psychological support they have. That doctor talked about the patients “who condemn themselves to loneliness and depression” after their diagnosis, by giving up any hope of living and isolating themselves from the world. Accordingly, they “almost condemned themselves to die of cancer,” even if their illness could be treatable.

Having those different responses from the patients, the doctors often prefer to notify the family of patients “in the worst cases,” and even use vague terms in those notifications, by saying that ‘He has few months to live. I think you should be prepared for anything in emotional terms.’” When the patients or their families ask whether the patient will survive the illness, and how many years can s/he live, the doctors often give rough percentages of the patients who survive the same type of cancer and live more than five years. However, when most patients do not know whether or when they will die of cancer, dying can become a long process without a clear beginning and ending for them, and that process is hardly a “private and lonely experience,” as Bauman argued. Most patients actively gather their close family members and other people who are close to them, and delegate to them certain roles and tasks, which ensures for them a sense of continuity after death, as I discuss in the following sections.

**Dying at Home or at Hospital?:** When the doctors at Güvercin and SSK realize that they will lose a patient soon and there is nothing left to do in medical terms, they suggest to the families that they should take him or her to their house, so that he or she will have a “good death” at home. They also prescribe high doses of painkillers, so that the last days of the patients would be as peaceful as possible. Several scholars, such as Susan Sontag (1978), Philippe Aries (1974) and Margaret Lock (2002) talked about the modern definitions of good death (while sleeping in one’s own bed and without having pain) and a bad one (dying of a painful accident or illness). A good death also means dying with dignity, when people still have a certain capacity to control their lives, as opposed to the “mechanical and dehumanized” death, which often takes place in hospitals (Sudnow, 1967). Philippe Aries (1974) uses the term “invisible death” in describing

death in modern times, when “the dying person is expected to die out of sight in a hospital where death is brought under full control with the discipline and anonymity of the medical order”(Palgi and Abramovitch, 1984).

Both the health care providers and the patients I interviewed have similar views about good and bad death, and the patients prefer to die at home, “where they feel the most comfortable,” in Altan’s terms. However, as a doctor at SSK mentioned, most deaths due to cancer still takes place in the hospitals, despite their suggestions to the families to take their patients home. That doctor explained that most patients and their families change their opinion “towards the end,” by saying that the dying patients would be better taken care of in the hospital and the family members would cope better with the whole process in the hospital context. Although I did not witness a dying patient at SSK<sup>42</sup>, the health care providers there argued that this process is not that mechanical, dehumanized and anonymous, since they allow the family members to enter the room of patients and “even form loud crowds” in the corridors. A nurse said that even if those crowds prevent the health care providers from passing through the corridors, and their loud cries demoralize the other patients, they try to be tolerant as much as possible, since they have lost or are about to lose a loved one. She talked about the family members who even brought the favorite food of cancer patients, which could be smelled through the corridors and wards. This description of patients who are dying at SSK contrasts with the arguments that dying is mechanical and dehumanized there and that death is a “lonely and private affair.” Thanks to the hospital policies, dying patients are often surrounded by

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<sup>42</sup> The patients rarely die, when they are in the Güvercin hospital, since they only go there for their routine examinations, tests, chemotherapy and radiotherapy. The hospital does not have wards, where the patients stay overnight, unlike the SSK.

family members and other people close to them “until the last moment,” which is also decided together by the family members and medical staff.

One doctor at SSK explained that they also turn the machines off whenever the family members want them to be turned off, since organ transplantation from cancer patients are extremely rare<sup>43</sup>. He explained that very few utterly desperate people would want an organ from a deceased cancer patient, both because of the taboo of cancer and the possibility that the cancer has affected the harvested organ as well. I also noticed that the wards where patients often stay for several weeks or months look more like living rooms than hospital wards. They are full of personal items, such as colognes, lotions, flowers and framed pictures on the bedside tables, with patients’ own nightgown and slippers by the bed. Several patients also made their family members bring their favorite pillows and blankets in order to feel at home.

Despite those efforts to make the hospital a comfortable place, some patients, such as Abdullah, said that they were tired of seeing the health care providers all the time, and that they want to see them only when they really need their help. Abdullah said that he refuses to go to any hospital except for his regular radiotherapy session, partly because of the health care providers’ bad attitude towards him. He also said that he has the “luxury of having a small health clinic in his neighborhood,” which “sends a nurse to his house to inject his painkillers when his chest pains become worse.” He said that he feels instantly bad both in psychological and physical terms whenever he enters through the door of any hospital, and most days he has no energy even to get out of his bed. He was grateful to

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<sup>43</sup> Aslihan Sanal’s (2004) article on organ transplantation indicates that organ donations and organ transplantations from cadavers are still rare in Turkey, despite the campaigns of the Ministry of Health and other related health organizations. Sanal argues that the problems in the legal procedures on organ transplantations, the general skepticism and reluctance in the society on organ donation, and the sensational news on the Turkish media on organ trafficking are the major reasons behind the low rates of organ donations, despite high rates of demands for organs, especially kidney in the society.

his daughter and wife who go to SSK and Güvercin without him to provide his medications and solve bureaucratic issues about his insurance. Abdullah mentioned that he stays in the hospital for a very short time, and that he leaves as soon as he has done with his therapy, since his biggest fear is also to die there. That fear is also related to how he felt uncomfortable and alienated in the hospitals in social terms, “no matter how many family members accompany” him.

**Cancer Patients and their Views on Death:** The ways in which the cancer patients talked about death and dying reflected the argument of Sharon Kaufman and Lynn Morgan (2005) that “who can speak about death to whom” and “the ways in which emotions are revealed or concealed are socially elaborated and bureaucratically determined.” Accordingly, for the cancer patients I interviewed I was a “young student” who conducts research in the hospital, and the ways in which they talked about death were influenced by how they viewed me and in which context we met and conducted the interview. The patients over fifty- five used phrases as “Of course, you would not know” and “You are too young to even think about those kind of issues” when they talked about death. They often praised the health care providers’ efforts “to save their patients,” thinking that I have professional or personal connections with them.

The interviews revealed a range of attitudes toward facing death. At one extreme, the most common was to never mention the words death and dying intentionally or unintentionally, ignoring the association between cancer and death. These often took place in the hospital setting, where the health care providers, also never utter the word death, could easily hear us. This was the case with 16 out of 28 patients who were under fifty year old, and their cancer was diagnosed in its earlier phases. Ten patients, who

never talked about death, also expressed their trust in the efficacy of the health care providers in curing their cancer. Of those patients who had a firm belief in their treatment, eight were treated at Güvercin hospital and five of them also emphasized that they had no economic problems related to the costs of their treatment. Those five also mentioned that they “may easily go abroad” for their cancer treatment if their cancer cannot be cured in Turkey<sup>44</sup>.

In contrast, four patients several times stressed the possibility of their death due to cancer and talked about a detailed plan of what they would do with their lives until they die. I conducted those interviews in the patients’ houses, where only the immediate family members could hear us, and therefore they took longer and became more personal. Three of these patients were over fifty year old and their illness was diagnosed in stage three or four, when it had already spread to several organs. Those three patients also had problems about their treatment costs or having insurance.

Just as whether or not the patients’ associate their illness with death, *what* the patients think about that association also varied in accord with their illness experiences, age and socio-economic status. Eight patients talked about the possibility of their death from cancer, and three of them emphasized that this is “inevitable.” In accord with the Bauman’s (1992) view of death as a lonely and private experience in modern times, the patients related their own dying with separation from other people, even well before their death. Abdullah argued that having cancer isolated him gradually from the outside world,

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<sup>44</sup> According to a recent press release by the Turkish Chamber of Medicine, the number of people who prefer to go abroad, especially to the U.S., for their cancer treatment has increased significantly since the 1990s. Although that press release does not include specific numbers, it gives an estimation of one out of every five cancer patients, who were treated in the private hospitals in Turkey, also had part of their treatment in the U.S. or in Europe. The press release is critical of that “Trend,” arguing that “our doctors are as skillful, if not more, than the doctors there,” and they are much more experienced because of the recent increase in cancer rates. (TTB, 2003)

and “prepared the people” for his death, just as the doctors kept saying: “People in the outside world, who do not see me much lately, will eventually hear about my death, and it will be much easier for them to cope with it, since they will just say, oh we knew that he was sick and bedridden for a long time. They will not remember much of the healthy Abdullah anyway... I am out of sight now, and one day I will be gone completely.” The patients also described death as the most personal and private issue, which should be the concern of the people who really care for them. However, Abdullah is also concerned about how “other people” would react to their death because of cancer, and he his view of death is far from being a “lonely and private experience,” since he knows that his close family members will always be with him until he dies.

Abdullah’ s wish “to vanish from the earth without bothering people if possible” is also related to the intolerance of health care providers in listening the complaints of patients and the general fear of cancer among the people around Abdullah. That fear is obvious in Abdullah’s remark that many people reluctantly listen to him when he talks about his illness since “they are afraid that they will catch cancer” and be sick like him if they listen to him too much. Yılmaz also said that if he dies people would be more upset to learn that he died of cancer at such a young age (in his fifties), but they will also think that it is “typical, given the high rates of cancer in Turkey. He stated that all that suffering made him more at ease with the idea of death and its inevitability, since both having cancer and undergoing cancer treatment helped him to “understand what his death may be like.” The views of Yılmaz and Abdullah indicate the modern distinction between one’s own and somebody else’s death, which Aries (1974) discusses, and that death is still feared, even it happens to someone else, but it is also seen as inevitable, especially if it follows a “typical” lethal illness, such as cancer. Here, dying of cancer is a

double taboo because of the fear that the illness induces in others, and because of the high rates of cancer mortality and its visibility in Turkey.

Death can hardly be thought of merely as a bodily change, since the patients can only think about dying in terms of the possible ways of experiencing it. However, the patients relate dying to the bodily changes that are brought about by their illness. Both Yılmaz and Abdullah emphasized that although the doctors were doing their best to save their lives, the cancer “gives signs” that their death is near, such as sharp and ongoing pain and extreme tiredness. Yılmaz and Abdullah confessed that they suffered so much during their treatment that several times they wanted to die in order to stop their suffering. Abdullah said that he asked his doctors and his wife many times to kill him by giving him an injection or a lethal combination of drugs, and complained that they never took him seriously. Yılmaz also explained that he would understand that his death is “about to come” when he would feel the sharper version of the burning pain in his chest, and that he would do his best so that “everything takes place as quickly as possible” at that moment.

Abdullah also explained that although his wife and children are really upset too and do their best to prepare themselves for his death in emotional terms, they try not to show all that to him and kept saying that he would be fine. Even right after my interview with him, which took place at his house, his wife came into the room and told him that she watched the news about the opening of a Japanese Garden on TV, and that the garden is not far from their house. She said that in the springtime when he would be fine (my interview with him took place in February), they would go to that garden together in order to see the blooming trees. Abdullah said that his family witnesses how much he suffers on a daily basis and they would be even more upset when he would “be gone”: “I will die once, but my wife and children die almost everyday when they hear me crying in pain.

When I am gone they will be more upset than everyone in the funeral, not only because they were the people who are closest to me, but also they have seen how much I suffered for months.” Abdullah also differentiated his immediate family who actively helped and supported him during his cancer treatment from the people who only noticed that he vanished and did not even bother to come to his house once they learned that he has cancer. He said that they would barely feel anything when they learned that he died, and they would come to his funeral mainly for socializing with other people, unlike his family, who would be devastated.

**Death, Survival and Fate:** In contrast to Abdullah and Yılmaz, Figen and Lale, second-phase breast cancer patients in their thirties, stated that “having cancer does not necessarily mean that they will die earlier than the healthy people” in Figen’s words. The fact that Figen and Lale challenged the association between cancer and death is not only related to their young age and relatively less developed cancer, but also to their belief in the efficacy of the medical treatment and their religious views on life and death. Figen said that even if she has a bad illness, she is treated at SSK, which has the best oncologists in Turkey, who do their best to save her: “Maybe my chances to survive cancer and live for a long time are much higher than a perfectly healthy person who goes out to work everyday. Even if that person is healthy, he could have a car accident and die in few hours, you never know. In the issues of health and sickness, I fully trust the doctors, who are treating me now; on the other hand, nobody but only God knows when one will die. This is also valid for the births, since all those wealthy couples try to have a baby for years by using all sorts of fancy medical technology, but cannot succeed in it. Then you hear about teenager girls who become pregnant by mistake! Birth and death are

like big brackets, and God only knows when, where and how to put those brackets. Sicknesses are just small parentheses within those brackets, and it is the doctors' job to take care of them."

Both Figen and Lale, who described themselves as "somewhat" and "sort of" religious, since they cannot follow most of the rules which do not fit into their everyday lives, believe that they have combined the necessities of living a modern life and their religious beliefs. Like Figen, Lale argued that religiosity has more to do with accepting God's power concerning the ultimate life and death issues, which the human beings do not have the power to control, rather than dressing in a religious way or practicing religion regularly: "I think there are a lot of young people like me in Turkey who think that religion has more to do with people's views than their behaviors... Why and how we are born, and when and how we will die are the ultimate questions that people try to find answers for, and 'only Allah knows all this' is the answer that we, the Muslims, give to those questions. Besides that answer, the dress, the turban, how many times you should pray and how you should pray are only minor details, which change from society to society in the Islamic world. I, of course cover my head in the mosque or in a funeral, but I can never see myself wearing a '*burka*' no matter where I will go or how Islamic this country will become." Lale also suggested that people do their best to live a healthy life and recover from their illnesses in cooperation with the medical doctors, but then it is up to God, who will certainly see those efforts and hear the prayers of the patients and their family members, whether anybody will survive an illness. It is interesting how Lale and Figen combine their views on the God's will and belief in modern medical practices harmoniously in their explanations about "life and death matters," despite the secular roots of the biomedical discourse.

That combination is also due to the fact that they see the realm of medicine, where the doctors do their best to save their patients' lives, as separate from the religious realm, where the God gives the ultimate decision about who will die and survive. Although that type of compartmentalization is typical in the mainstream religiosity in modern Turkey, it is also related to those cancer patients' hope to be saved by the medical doctors. In the case of Figen and Lale, they believe that if they and their doctors would do their best to treat their cancer, then God will see and appreciate those efforts as well. Ayhan also said that the idea of fate (*kader*) in Islamic belief does not necessarily mean that people leave everything up to God and do nothing to improve their health, in contrast to the views of "extreme modernists," including many health care providers. Ayhan talked about a doctor in another SSK hospital in Istanbul, whom he overheard mocking two women with headscarves, by saying that they did not need to come to the hospital since their prayers would be more effective than the treatment. Ayhan said that these women did not react to the doctor, possibly since they were used to such comments, but he thought that that comment was not only unfair, but also simplistic and Orientalist. He stressed that religious or not, people would come to the hospital when they have a major health problem, and that shows that their trust and belief in modern medicine, which "has nothing to do with their religious beliefs."

Four patients also talked about dying as being their fate, either because of cancer or for any other reason, and they also emphasized that "they do their best to delay it," as Altan mentioned: "Of course, you want to live as much as possible, and this is especially true in my case, since I worked very hard for decades all over Turkey as an architect and had wonderful plans for my retirement. I bought a house by the seaside in a small Aegean village, near Foça, and I was planning to live there with my wife and spend my

days fishing, swimming and just being lazy. I had to delay all those plans because of my treatment, but I am still determined to go there to realize my plans once I am totally cancer-free, so I do everything that the doctors tell me to do, and I also look on the internet for other scientific ways for a quick recovery. So, I do not want to offend God, but I have no intention to die of this illness (he laughs).” Interestingly, only six out of fifty cancer patients directly referred to God and Islam when they talked about death and dying, and how those patients related death with Islam did not contradict biological explanations of death and dying and modern lifestyle, as I discussed above. For instance, they talked about death as the ultimate ending for their life, body and soul, but they did not mention such concepts as immortal soul, heaven and hell.

In the interviews, I felt a general reluctance to speak about religion with respect to having cancer and death, and in general, except for the interviews with Ayhan and Feriha, possibly because I was a student and researcher who they met in the hospital, and because most interviews took place there. Although the extra “smoking room” was provided for my interviews at Güvercin, the doctors and nurses could enter there easily during our interviews, and could listen and occasionally interrupt. The patients also closely associated death and dying with their cancer experience, and they gradually internalized the medical and biological explanations on their illness, which are regularly provided by the doctors and nurses during their long treatment. Therefore, most cancer patients refer to religion and God in talking about dying and death only in a rhetorical way, and stressed that they could survive cancer and live a long life thanks to their efforts to have a healthy life and also because of the efficacy of their medical treatment.

**Dying as a Liminal Process:** Margaret Lock (2002) writes about the liminality of dying, and argues that “dying is usually thought of as both event and process.” The liminal period covers “the ambiguous time of biological, spiritual, personal, and social transformations associated with dying and death.” The people who are close to a dying person also experience that liminal period, albeit in a different way, when they have to recognize that a person close to them will die soon and cope with the ambivalent emotions that are brought by this recognition (Palgi & Abramovitch, 1984). When one’s death is expected soon, as in the case of some cancer patients, one has to deal with certain social and material matters, such as inheritance and the continuity of his or her own family line. Those arrangements also indicate how the dying individual tries to achieve continuity in the social order around them, despite the discontinuity of their individual life, which may happen soon (Lock, 2002).

Those arrangements also help dying people experience death as a more social rather than a lonely and private process, as argued by Bauman. Patients plan those arrangements, and decide who to involve during the liminal period, if their health condition permits such arrangements and the doctors approve them. The views of dying as a “liminal process” and continuity after death also challenge Bauman’s argument about the modern conception of death as the “absolute nothing” which resists any meaning. Several Turkish patients are able to visualize a meaningful continuity for themselves, *after* their death, mostly through family members who will survive them. In chapters 4 and 6, I discussed how having a cancer diagnosis and undergoing cancer treatment made most cancer patients re-evaluate their social life and differentiate the people who are “close to them” and the “others” who fail to understand and empathize with what those patients were going through. During the liminal period, when the patients think that they

may die soon, they also often make a greater separation between the people who are really close to them and the others, as Abdullah did. However, they may also further their bonds with the former, while completely isolating themselves from the latter, as the examples that I will discuss in this section indicate.

The arrangements and transformations that the cancer patients experience during the liminal period also make them re-evaluate their past, present and future, similar to the ways in which they revised their lives in formulating their illness narratives. Selma and Gülsüm said that having cancer led them to revise their lives and focus on which of their future plans they could or could not accomplish, which gave them an extra motivation for surviving. The future plans also include items which may alter the private and public aspects of the patients' life, as well as the life of people who are close to them. Gülsüm, who was cancer free when I interviewed her, said that there was a time when the results of her chemotherapies did not come up well, and she was truly demoralized for the first time since her diagnosis. Then, following the suggestion of a friend of hers, she made a list of things she wanted to do in the future, and the items on her list included taking a trip to Paris, organizing the wedding of her son and seeing the birth of her grandchild, which was on the top of her list. The last two items can be interpreted as an effort to transcend death, at least symbolically, by establishing means for biological, social and cultural continuity (Palgi& Abramovitch, 1984).

Gülsüm said that since her son is an only child and his father died when he was in his early twenties, he could hardly cope with her illness, which was more bad news for him just a few years after his father's death. Therefore, she did not want to put extra pressure on him in terms of his personal life, education and career: "My son was 26 when I was diagnosed with cancer, and he was still trying to cope with the death of his father in

the earthquake, which took place four years before my diagnosis. At that time he was dating a girl, who was not that pretty or special, but she was a very good girl and she liked him a lot. She was by his side all the time. I thought that they can lead a very happy life together, but my son was telling me that he was too young, he was not in love with that girl and that he even thought about ending their relationship...However, after I made that list of the things that I really wanted to do in the future, I sat down and had a talk with him. I told him, as frankly as possible, that I may not have much time left in this world and I would be extremely happy if he marries that girl and I could organize his wedding. I did not talk about having grandchildren in that talk in order not to panic him too much, but I think he really got my message... In June, they had the most elegant and fun wedding that I have ever seen, and, for the six months after the wedding, they still seemed pretty happy to me. While organizing the wedding, I was also the happiest person in the world, and the whole thing might have also speeded up my recovery.”

Gülsüm’s wish to organize her son’s wedding and seeing the birth of her grandchild before she would die indicates her wish to continue her family line and her association of her death with other typical rituals that mark different phases in the life-cycle. The ways in which she talks about organizing her son’s wedding and the wedding itself also echoes Turner’s (1969) argument that people seek out ritual practices that guard and guide them through the transitions they experience during liminal periods (Kaufman and Morgan, 2005). Gülsüm describes organizing her son’s wedding as a therapy in and of itself, which might be even more effective than the medical treatment that she was receiving, in giving her the psychological strength that she needed to “fight with cancer.” “The most elegant and fun wedding” that Gülsüm had ever seen was also

presented probably as a powerful contrast to a solemn funeral, which could have taken place at the same time.

Selma also talked about how her future plans changed while having cancer treatment, because her doctors told her that her ovaries could be removed if her chemotherapy was ineffective and she may not have children in the future. She said that since she grew up in a poor and crowded family with many small children around, having her own house and her own business, rather than having a child, became her priority. However, when the doctors talked about her risk of never having children, she began to look at her life through another perspective and asked important questions: “If I die because of cancer in a couple of years what will be missing in my life? Is there any major aspect of life which I have not experienced yet? When I try to answer those questions, I realized that I achieved most of my major goals so far. My textile company is doing OK and I have a small house in a nice neighborhood in İstanbul, but for the first time in my life I began to see my being single and not having a child as a problem. This happened also because my family and doctors kept talking about this issue with me in the last few months. My parents and siblings were constantly insisting that I should marry and have children, and they put even more pressure on me after my diagnosis... As for the doctors, they probably think that my cancer will get worse through time, and suggest that I become pregnant soon, while my health still allows it. Being influenced by all those things, I also began to think about adopting a child, if I cannot find someone I can get along with. Now that I am an independent woman in all terms, I cannot just marry anybody in order to have a child. When I told my friends and siblings that I had begun to warm up to the idea of having children, they were actually pretty shocked, since they never expected that from me.” Selma also argued that the possibility of losing the ability

of bearing children led her to understand the importance of having children, not just for herself, but for the whole family, since her child may be a “souvenir” from her if she “would die soon from cancer.”

The change in Selma’s views about having a child cannot be interpreted only by her wish to achieve biological continuity, but also her wish to prove that she can raise children in a better way than her siblings: “Even if I die of cancer when my child would be less than ten years old, I know that the education in the earlier years makes a crucial difference in child education. Even if I die when he or she grows up, I could be a good role model for him or her, in terms of my education and business career... Since I am the most educated person among my siblings and I am very close to my nephews and nieces, I believe that I can be a better parent than my siblings. I do not want to offend them, but I often see the mistakes that my siblings make when they raise their child, and my nephews and nieces come up to me rather than to them when they have a problem or when they need an advice from a grown up person. I also help them when they do their homework and when they study for the high schools’ entrance exams... Therefore, I can see myself being a good mother if my health allows me to give birth and raise my child.” In this quote, besides the sibling rivalry, we can easily see that Selma’s wish to have a child is a wish not only for biological continuity, but also a social and cultural one. It also indicates that the symbolic capital, in Bourdieu’s (1984) terms, Selma brings to her family, should be transferred from one generation to the other. According to Selma, having a role model like her, her nieces, nephews and children, whom she may have in the future, will also improve the social status of their family, by fully adapting to the city life in social and cultural terms as well, which is a task that is not accomplished by Selma’s parents and siblings.

**Survival and a New Wisdom:** Selma, Gülsüm and Altan emphasized that fighting cancer and confronting the idea of death taught them valuable lessons for the rest of their lives and made them realize different aspects of their characters, which they were not aware of before. Although those three patients differed in terms of their socio-economic background, demographic characteristics and personality, they all believed that they had survived cancer. The health care providers described Selma and Altan as “almost cancer-free” and Gülsüm’s cancer treatment was over almost a year ago. The three patients believed that they survived cancer “since the worst part of their treatment,” in Selma’s words, was over, and they were no longer scared that their illness would cause their death. Therefore, it was easier for them to talk about death, which became an “abstract and far away concept again,” in Selma’s words.

Selma said that, despite the optimistic remarks of doctors about the results of her treatment, she could not help but think: “Will this cancer kill me?” since she knew that cancerous cells can spread out rapidly in young patients’ bodies. She said that “her questions about her life and death” also led her to worry more about her bodily changes due to cancer and cancer treatment: “When I have a sharp pain in my uterus area or when I absolutely have no energy, I keep thinking whether these are the first signs that tell me that the end is near. When I feel better again, I become very happy and think that bad phase is over again. Those phases taught me to enjoy every minute, when I feel good and healthy, thinking that I have dealt with one of the worst problems in life pretty successfully so far.” Similar to Selma, Gülsüm also said that she decided to enjoy her life as much as she can and realize her wishes without delay after her cancer treatment.

Like Abdullah, who differentiated his family members from the “others,” Gülsüm and Altan explained that their cancer also showed them who *really* cared for them and

who “just pretended” to do that, because they felt obliged to do so, and that they rearranged their social life by differentiating those two types of “friends.” Altan quoted Nietzsche’s saying, “What does not kill me, makes me stronger,” in order to emphasize how he led a better and simpler life, with more meaningful social interactions towards the end of his treatment. Those patients conveyed a message that they found a larger meaning, which indicates why they, *out of all people*, had cancer and faced death. They also believed that having cancer and undergoing cancer treatment have provided them with a new wisdom for their lives, which improved their life and character considerably. This message indicates that they “did not have all that suffering in vain,” in Gülsüm’s terms, and that surviving cancer enabled them to look back on what they experienced and think about it retrospectively in order to “digest the lessons” that the cancer has taught. For those cancer patients, the opposite of dying of cancer is not only surviving this illness, but also revising their life and social relationships in accord with their illness experience, learning a new meaning and having a new wisdom for the rest of their lives. That new meaning or wisdom often makes them live their life more fully and creates a new balance in their life, since the painful process of cancer treatment and what the cancer took away from the patients’ life and body are somewhat balanced with that new meaning or wisdom evident in the patients’ narratives.

The new wisdom of survivors is also a common theme in the written cancer narratives, since the “model patients” who survived cancer also see their illness as an “eye-opener,” which makes them see their life through a new perspective. These authors feel the need to tell other patients that they learned something new about themselves or their life through their treatment, which improved them and their life, despite physical and psychological suffering. They differentiate the old version of themselves before

cancer diagnosis and their new version after surviving cancer, which is often more open-minded, courageous and optimistic. Cancer and facing the idea of death often led to a transformation for those patients in spiritual terms, which make them live better, more meaningful and fuller lives. Fatma Babaoğlu (2006), a housewife in her forties, explains that cancer divided her life into two, since having cancer led her to realize that she was depressed before the diagnosis because of her stressful life and problems with her husband. In contrast, in the “after cancer” phase of her life she “opened her eyes” and learned to enjoy the small pleasures of life. She also started to pursue new hobbies, which she always wanted to pursue but had delayed for various reasons, such as painting, knitting and jewelry design. The spiritual transition also leads those patients to become better and stronger in psychological terms, and they gain self-confidence since they were physically and psychologically more equipped to win their battle with cancer. Esin Özbek (2006), a 45-year-old accountant in a private hospital, mentions that cancer taught her not to be angry at other people and to forgive them even though they made her very upset. She even forgave her ex-boyfriend, who she was with for seven years and who made her very upset, and she learned to accept everyone as they are, without trying to change them or being upset about their weaknesses. Although we do not know how her new ability to forgive influenced her social interactions, we know that it influenced her in a good way, since she thinks that being angry with other people harms herself the most in psychological terms. In contrast, Meryem Eraslan (2006), a painter in her forties, became more exclusive in her social interactions. Cancer taught her that her life is very valuable and that she should not spend it with the people she does not trust fully anymore. She states that cancer taught her to say no to those people in order not to be disappointed by them later on.

Through having cancer, Eraslan also learned that the beauty of a person's looks is temporary, and that the real beauty is the inner one, which means that one has enough love and compassion in her heart. Those statements support these authors' messages that having cancer is not the worst thing in life, and that it is not the end of life. The authors want to convince the patients that they can make something good out of even having cancer, which has many negative social connotations. Having cancer also leads the patients to revise their emotions and views on death, and "make peace with the idea of death" as we see in the example of Sibel Kalaycı (2004), who was terribly afraid of dying before her cancer diagnosis, since it reminded her "decay, bugs, mud and darkness." In contrast, after cancer treatment, she often thinks about her family cemetery and she will be a part of it, as well as planning what will be written on her gravestone.

The writings on what cancer taught those authors about being better people living better lives can also be read as an effort to find an ulterior meaning in having cancer and facing death, which, in contrast to Bauman's (1992) view of death that resists any efforts to give meaning. Through their efforts, the authors differentiate themselves from the "weak and pessimistic" patients who accept cancer diagnosis as a "death penalty" in Kalaycı's (2004) terms. Those authors focus more on how they overcame the difficulties of having cancer treatment and facing death, rather than what those difficulties were and how they affected their emotions. This may be because of the fact that they want to emphasize that there is a solution for every problem that cancer causes. They even suggest that there are possible ways of facing death due to cancer, while still remaining strong and brave, as Sibel Kalaycı's remark above indicates. However, as I discussed in Chapter 3, this may not be too helpful for the cancer patients who read those books, which may make them feel inadequate in dealing with their own problems and prevent

them expressing those problems to the people who are close to them. This is especially problematic in the issue of facing death due to cancer, since death is frequently a topic which people avoid thinking and talking about as much as they can, especially when it is associated with cancer, as I discussed at the beginning of this chapter. However, the cancer patients I talked to *need to express and share their problems* in order to gain strength and courage to solve them, unlike the super hero-like authors of cancer narratives who seem to be born with the strength and courage to deal with having cancer and facing the idea of death due to this illness.

In this chapter I indicate that very few of the cancer patients were able to express their concerns about dying of cancer, and this ability depends on whether they think that they may survive cancer and their personal characteristics, as well as the attitudes of their health care providers towards dying. As I discussed in Chapter 4, the professional psychological support is also inadequate for the cancer patients, and visiting a psychologist is a taboo for them, except for the few patients with a middle or upper class urban background. Therefore, the cancer patients share their biggest anxieties about their illness and dying only with the people whom they feel close to, and these are the people with whom they share their illness narratives and experiences. The patients and people who are close to them become like “isolated islands” in the middle of the crowds who do not understand them, in Altan’s words, while dealing with the problems that are brought about by cancer, including the fear of death.

## **Conclusion**

### **Patients' Voices and Cancer as a Public Issue in Turkey:**

#### **Conflicts and Negotiations in Cancer Narratives**

When the people around me asked about my dissertation topic and expected a one-sentence answer, my formulated and easy answer was that it is about what Turkish cancer patients feel about having cancer and how they evaluate their illness experiences. Their reactions to my answer were often as vague and general as my explanation, such as: “That is such a pessimistic topic. Don’t you feel bad when talking to or writing about those patients?” Only few people asked me “So, what do they feel?” which was a more difficult question to answer. Even without having to talk to cancer patients, one could easily guess that they would feel rather shocked, panicked, afraid and sad, and think that it is the job of the psychologist to study those emotions. However, how the cancer patients feel was closely related to the conception of cancer in the society and the medical realm, and the emotions of the cancer patients I interviewed can best be summarized as frustration and anger because of not being heard. As Yılmaz said: “Doctors, politicians, journalists, you name it...Everybody seems to have an opinion on cancer in Turkey, but no one understands what we, the cancer patients, think and feel, although it is *us* who suffer from that illness. They do not even bother to listen to us. They simply do not care about us.”

This problem was expressed by most of the cancer patients I talked to, which made them angry and frustrated, since in the words of Gülsüm “the health care providers are interested in what is happening in their body rather than what they experience as a cancer patient.” I believe that their anger and frustration had valid causes, even though I

was more of an “outsider,” someone who happened to be interested in their illness narratives. During my fieldwork I was also concerned about the diverse explanations about why the cancer rates have increased in Turkey, what people should or should not do in order to avoid cancer, and how the medical treatment can be more effective and less harmful in terms of its side-effects. These aspects arose from the different and conflicting views of the health scientists, health care providers, as well as politicians, journalists, activists and the “lay people” who participate in the debates about cancer and cancer patients. The professional authority of health scientists and health care providers and the lack of a social platform where the parties can communicate with each other and share their views, prevent each voice being heard equally. The cancer patients suffer the most from that deprivation.

In many accounts of cancer, the patients’ voices are rarely heard, with the exception of the illness narratives of a few public figures. This results in most patients feeling marginalized and discriminated both in their social lives and during their medical treatment. It also prevents them from finding their own words to represent what they experience, since the health scientists, politicians, journalists and activists propose their own accounts which patients are expected to accept. The patients’ efforts to give their own meaning to their experiences are often compromised by the statements of medical and political authorities. As a result, patients often feel reluctant to share their illness narratives with other people, especially with the health care providers, since they think that they do not have much value compared to the authoritarian statements in the health realm and in society. The patients who have difficulties in finding and sharing their views, even with the people who care about them, think that they have very limited control over the course and treatment of their illness. However, despite these difficulties,

Turkish cancer patients also feel the need to find their own words and meanings, which represent their illness experiences. They share their thoughts and experiences with a small support group, which they establish, since they believe that those efforts are crucial for their healing process.

The public debates on cancer and cancer patients are dominated by the discourse on the medical and political “war against cancer,” which focuses on the reasons behind the increase in cancer rates in Turkey and how to prevent people from having cancer. The popular media and the state’s health institutions attribute power and authority to the health scientists and health care providers, despite the disagreements among them in that important war. The health scientists and health care providers often call themselves the “health army” (*sağlık ordusu*), in accord with the dominant war metaphor, and demand the cooperation of the cancer patients as well as society in the battle against the “common enemy.” Accordingly, the main responsibility of the Turkish people is to live a “healthy life” (*sağlıklı yaşam*), regardless of their socio-economic background, demographic characteristics, and the environmental problems that affect them. Living a healthy life, which has become a fetishized life goal in the Turkish media and medicine because of its frequent use and the values that are attributed to it, often includes eating healthy foods, exercising, and having regular check-ups (Ahıska and Yenal, 2006). Those requirements were first emphasized in the 1980s, when the privatization in the health care started and health was considered an individual responsibility rather than a citizenship right, as in some other countries, such as the United States with its dominant private health sector. The requirements also increased the medicalization of everyday life are often vague and unrealistic achievements for many people with disadvantaged socio-economic backgrounds, who visit hospital only when they are very ill and who cannot treat their

illnesses at home. Moreover, those requirements may not translate into living a healthy life without major illness, because of environmental and genetic factors.

The cancer patients' full cooperation with the "health army" is more problematic, since the medical and political authorities often blame them for late diagnosis or risky behavior, such as smoking, and impose their own conceptions of cancer and guidelines on how to behave as a good cancer patient. Those impositions limit the patients' ability to develop and share their *own* evaluation of what they experience, and to make their own decisions about their cancer treatment. The health care providers expect patients to become their main helpers in the war against cancer, and to act as a paramilitary force in determining the war's consequences in individual cases. "Good patients" should thus strictly follow the treatment procedures without showing any sign of doubt, and always keep their morale high, no matter what happens during treatment. However, the patients, being real human beings with their own concerns and anxieties, cannot always passively accept those rules, even though in theory they respect the medical authority. Moreover, they often "betray" the health care providers by benefiting from complementary or alternative healing practices, such as using home remedies, since those practices are often an inevitable part of everyday life. For instance, several patients talked about visits to the saints' tombs together neighbors, an elderly relative or a friend whom they could not offend. The health care providers often see those acts as a "betrayal" of their medical authority and view them as "unacceptable," since they think they may damage the scientific and medical war against cancer. The health care providers also expect patients to provide only brief illness narratives, which focus on the physiological aspects of their illness experience, rather than the psychological, social and economic details.

The health scientists, health care providers and politicians who deal with health and illness issues focus more on why the cancer rates have increased so drastically and how to prevent that increase, rather than on how having cancer affects people and what kind of psychological, social and economic problems it brings to their lives. How having cancer and undergoing cancer treatment affects people's social position and interactions, personal identity and sexuality, and how the patients cope or come into terms with those problems, are in general underestimated. The illness narratives help us to investigate those issues, without which the debates on social, cultural and psychological aspects of cancer in Turkey remain inadequate. The health scientists and health care providers often view cancer patients as a mass of people who differ from the "healthy people" in biological terms, rather than focusing on them as individuals, or paying attention to the socio-economic differences among them. Therefore, as opposed to the multitude of opinions about the causes of cancer and how to prevent it, there is a considerable silence on what the cancer patients experience and how they interpret those experiences in their illness narratives. The medical and political authorities, who often speak on behalf of or for the patients, silence the patients' narratives, which adds to the taboo concerning speaking about cancer in Turkish society. Cancer remains the illness of "other" people, whose individual characteristics and social position are diminished and made invisible by their being cancer patients, who may also die soon, and who right after diagnosis are socially and emotionally separated from the healthy people.

The cancer patients who are visible as individuals in the public realm are the well-known public figures with a privileged socio-economic background, which provides them with a better access to media and also a privileged position in accessing health care. Those patients who often wrote and talked about their illness experiences after the late

1990s, have a retrospective approach in sharing their illness narratives *after* they became cancer-free and solved their cancer-related problems. These well-known people also avoid giving messy, personal details in their narratives, since they represent themselves as “model patients” who followed the medical guidelines closely. Their narratives rarely speak to ordinary cancer patients and their relatives, especially in the case of the patients with a disadvantaged background. Those narratives hardly fill the gap between the multitude of voices and the silence, which can only be filled by the illness narratives of patients from diverse socio-economic backgrounds. The construction and sharing of illness narratives are crucial not only for filling this gap, but also for providing patients an active role in understanding and evaluating what they experience.

The fact that personal and private aspects of cancer are largely underestimated in the public realm and health care also leads to a limited understanding of the causes and effects of cancer. As the oral and written illness narratives indicate, patients’ views of what causes cancer and how it affects them is an important and overlooked aspect of health care. Disputes about why cancer rates have increased in Turkey often result in the health care providers failing to provide a specific reason for the cause of cancer. Only in the cases of some male lung cancer patients, who are heavy smokers or who work in environmentally risky sectors, and a few female breast cancer patients with several female relatives who have the same illness, do the doctors speak about obvious causes. That vagueness also intrigues the patients, who sometimes provide their own explanations “to fill the gap,” or they take the cue from the health care providers about not dealing with the causes of their cancer.

Most cancer patients also dwelt more on how cancer affected them than on what might have caused their illness, since they were learning to live with cancer and adjust

their personal and social lives, and why they had that illness seemed less important. However, as I discussed in Chapter 4, some patients have broad interpretations of what may cause their cancer, and think that it could be explained by “not fitting the social norms and expectations,” such as having a divorce in an old age, or not wanting to marry and have children. In those cases, having cancer makes the patients re-evaluate their “unusual” life choices and redefine themselves as individuals, insisting on their own plans for life, even though those plans have separated them from the healthy people, in both biological and social terms. Some other patients also had local views about why they became ill, such as eating a very cold watermelon as a cause of stomach cancer.

The cancer patients also construct their illness narratives in order to resist their social marginalization and exclusion. One of the main aims in constructing narratives is to share them with people who understand and empathize with them. The patients’ decisions on when, how and with whom to share their illness narratives lead them to form small groups, which consisted of people who are close to them. The patients thereby gain a sense of control over the course of their illness by forming the group and having a micro-management within it. They often tell these people when and what kind of help or support they want, such as accompanying them to the hospital, solving bureaucratic problems about insurance, providing medication and showing emotional support. Most of these illness narratives include the acknowledgment of help and support by the people in the patient’s small group, which possibly motivates them to continue to help the patient in the future.

My dissertation indicates that throughout cancer treatment, when most patients gradually face the loss of their hair, breast or a major internal organ, and they contemplate the idea of death, they strengthen the boundary between them and “other” people. By

contrast, their small social group becomes more cohesive in emotional and social terms, to the extent that the illness experience becomes increasingly communal rather than individual. Sharing illness experiences and narratives within that group become increasingly crucial throughout the course of treatment, although not all patients are lucky to form such a group and guarantee its persistence. Despite the idealized image of Turkish society, where family and community ties dominate, those ties are sometimes severed by migration patterns, economic problems, generational conflicts and the problems that cancer causes. The taboo around cancer and cancer patients, which is mostly related to its association with death, may gradually damage long-term friendships and personal relations, and some patients thus form very small groups of support. The illness narratives have the potential of breaking the taboo on cancer, helping to maintain the ties between the patients and their small group, as well as providing a sense of continuity in the patient's life.

Social scientists who analyze illness narratives indicate that through narratives ill people build a bridge between individual and social or cultural realms, as well as between what is private and public, and they also create a sense of order and continuity out of rupture (Garro and Mattingly, 2000). Linda Hunt (2000) explains that chronic illness “can produce major disruptions to the core components of a sense of self, such as social roles and relationships,” and in these cases, illness narratives “hold the potential not only of articulating the disruptions experienced but also of reconfiguring one's very social identity.” Through telling illness narratives, ill people also influence how their illnesses and their selves are understood by others, rather than passively internalizing the imposed conceptions of their illness. Therefore, the very ability to construct an illness narrative, which represents personal, bodily and social experiences that are brought about by the

illness, and convey it to different “audiences,” is empowering for the patients in psychological and social terms (Mattingly and Garro, 2000). However, the patients’ ability to construct and share their own illness narrative also depends on their social environment, and Turkish cancer patients rarely find that opportunity in their social life and medical contexts, where “non-scientific” views are rarely accepted. Turkish health scientists and health care providers claim that they know the ultimate truths on the issues of cancer, since their views are based on the most recent and “superior” scientific knowledge, despite the fact that there are disagreements among them. They also devalue “popular” views, considering them to be superstitious myths and biased. This too, creates an imbalance in the already limited degrees of communication between the “scientists” and “lay people.”

As my research indicates, cancer is readily associated with recent social changes in Turkey, such as the rapid urbanization and industrialization. Most doctors also continue to internalize the task of guiding Turkish society in the seemingly ever-lasting process of modernization, which also includes constructing a “healthy” social life. They also have norms about how the cancer patients should view their illness and what they should or should not do so that their treatment will be effective. Those norms often include the idea that patients should keep their morale high no matter what happens in the course of their treatment, should fully respect the doctors’ decisions on their treatment, and avoid home remedies or any other kind of alternative or complementary treatment. Those norms, although unrealistic for many patients, correspond to their views about “ideal” or “model” patients, who often have an urban, middle or upper class backgrounds, and who fully believed in, or are actively involved in the Turkish modernization process. These elite and educated patients believe in the power of modern sciences and medicine

in treating cancer, feel “at home in the hospital,” and view the health care providers, who take care of them, “as close as their family members.” In contrast, the “other” or “bad” patients feel marginalized or discriminated against in the hospital, as a result of the tense and aggressive attitudes of health care providers and exclusionary practices of other patients who often sit far away from them in the waiting room and avoid conversation.

The “bad patients” are often the first or second generation of migrants to the big cities, such as İstanbul, and their social lives and cultural values are different from the old elites, who feel threatened by that difference and by the way the “newcomers” are changing the city. The conflict between the old modernist elite, who are losing their political and social power, and the “newcomers” or “invaders,” who claim that a more inclusive and flexible modernity is possible, also take place at a societal level. The social changes in Turkish society, which began in the 1980s, raised a new political consciousness in many people, based on their ethnic identity, religious beliefs and local issues. In the 1990s, they founded the Kurdish and Islamist social movements and political organizations, and raised a new social awareness. Those movements and organizations have created a serious challenge for the Kemalist elite’s vision of Turkish society, which is unitarian, closely tied to the state and its policies, and includes the top-down and state-led modernization project. The Kemalist elite, whose social status is largely dependent on that vision, has tried to maintain their “elite” status by strengthening their boundaries between them and the “others.” These efforts take place through underlining the difference between their own cultural values and those of the “others,” as well as by limiting the access of the “others” to political power. The boundaries are also regularly manifested, tested and negotiated in the social encounters in everyday life, and in the people’s clothes, dialect and body language, which give clues about their socio-

economic background. My research indicates that the process of boundary formation further marginalizes the “bad patients,” those with a rural and religious background, because of the close association of Turkish medicine with modernist ideology and practices.

What the “bad patients” experience is a part of larger social and cultural processes of exclusion and discrimination, which interact with the political and economic inequalities. In their report, Fikret Adaman and Çağlar Keyder (2006) argue that poverty, dissolving family and community ties because of migration, lack of access to primary education and health services and spatial discrimination<sup>45</sup> also play a crucial role in the reproduction of discriminatory processes. The authors claim that social discrimination in Turkey takes place on multiple levels, which support each other and which create a vicious circle. This adds to the social suffering of many people, especially recent migrants, who also have limited access to health care facilities and providers. Adaman and Keyder also indicate that the problems of discriminated people in having access to the basic civil rights, such as the right to health, are left largely unaddressed in the public sphere, in the media and by scholars and academicians. They argue that major political, economic and legal changes are required so that the discriminated people can participate fully in the social, economic and political life, and the vicious circle of discrimination can be broken.

My dissertation addresses these issues of discrimination through the perspective of cancer patients’ illness experiences and narratives. It focuses more on the social and

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<sup>45</sup> The term “spatial discrimination” refers to the fact that the poor and discriminated people live together in the same neighborhoods, such as Okmeydanı where the SSK hospital is, or squatter areas, where the housing quality is low and infrastructure is inadequate. The people in those areas are also largely isolated from the social life in the cities, since they have a limited access to the cultural and social institutions.

cultural discrimination, than on the political and economic ones, since it prioritizes the meanings that patients attribute to their illness experience. However, it also acknowledges the political and economic issues, which the cancer patients connect to their illness experiences, such as the crowds in state hospitals, bureaucratic problems concerning health insurance, difficulties in finding or buying the necessary medications. I also draw attention to the issues of poverty and the debates about Turkish modernization, rising Islamism and globalization. Cancer patients combine their understanding of their illness experiences with the larger social and political issues. In this way, they bridge the gap between the personal meaning they attribute to their illness and popular social and medical conceptions. Nevertheless, the overpowering medical conceptions of cancer stifle the individual voices of cancer patients, and hinder their ability to fully establish their agency and a sense of control over the course of their illness. The fact that patients who are categorized as “bad patients,” both in medical and popular discourses, makes them defensive, and causes them to feel “out of place” in the hospital. Many are also reluctant to share their illness narratives, even with the small group of people who are close to them, since they do not want to upset them any further.

**Possible Solutions to the Cancer Patients’ Problems and Suggestions for the Turkish Case and Social Sciences:** In order to arrive at a better understanding of what Turkish cancer patients experience and how they interpret those experiences, the voices of cancer patients from various socio-economic backgrounds should be heard both in the health realm and in society in general. The Turkish health care providers and health scientists, who have very little or no social science education, should understand the value and importance of illness narratives, not only for diagnostic purposes, but also to

empathize with what patients feel during their treatment. That is crucial for patients who cannot afford or who are reluctant about receiving professional psychological counseling, and who also lack family or community support. Doctors also should pay more attention to the illness narratives in order to bridge the ideological and social gap between them and the patients, which affects their practices. However, this cannot be easily accomplished, since it requires that health scientists, and health care providers develop a critical perspective towards the exclusive biomedical discourses and practices and the association between Turkish modernity and medicine. Medical education in Turkey consists largely of the transmission of the biomedical knowledge and practices, which is considered the main aim in studying medicine. The few courses about the history of medicine, medical ethics and psychology are inadequate both in terms of their content, which is devoid of the recent theoretical developments and debates in those fields, and their marginal importance in the eyes of medical students and most faculty members<sup>46</sup> (Terzioğlu, 1998). Medical education also has to take a holistic approach, by investigating the psychological conditions of the patients, as well as the economic, social and environmental aspects of health and illness.

Developing a holistic approach is crucial for treating cancer patients and dealing with the problem of increasing cancer rates. The rapidly increasing cancer rates and the fact that cancer affects people from different socio-economic backgrounds in different regions of Turkey, have lead to the perception of cancer as an epidemic, which threatens

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<sup>46</sup> When I interviewed the doctors for my master's thesis and asked about their university education, most of them considered those "social" courses the "light ones," which serve to raise their GPA. They described those courses as based on lectures, with very few or no debates, and they said that "just memorizing few basic statements and pieces of knowledge" help them to have a good grade. The faculty members also stressed that the "young doctors" will learn about how to approach their patients and solve the ethical problems while they practice, and what they learned about those issues in the school only provide a basis of what is right and wrong.

the whole society. In order to understand the social, demographic and environmental characteristics of that “epidemic,” more detailed and accurate statistics on cancer and cancer patients are required. In addition, more research on cancer and cancer patients, based on both quantitative and qualitative research methods, are needed in order to achieve a better understanding of the political, economic and social aspects of cancer. These projects require close collaboration between public health specialists, epidemiologists and oncologists, as well as a collaboration between health scientists, health care providers and social scientists, which hardly exist at the present time in Turkey. Such collaborations must be in the form of a team work, where the interactions among scholars takes place on an equal rather basis, and this can only be achieved when the social scientific research and perspectives are valued as much as those of positive sciences. That will, of course, take a long time, since it requires challenging the association between Turkish modernity and modern sciences and technology which has existed since the late 19<sup>th</sup> century.

The recent heterogenization in the socio-economic background of doctors may be helpful in that process, since a new generation of doctors, who subscribe to different political opinions about Turkish modernity, are raised and started their professional careers. However, inequalities among the health scientists and health care providers, in terms of the professional status may create problems in building egalitarian interactions in teamwork. Accordingly, the oncologists and surgeons, who use the latest medical methods and technologies often view the work of epidemiologists and public health specialists as “lighter” or less important than theirs. As I discussed in Chapter 4, the doctors and nurses who work at the state hospitals also often complain that they do not have time to do research because of their workload in the hospital.

Since the 1980s, very few Turkish social scientists, mainly the sociologists, anthropologists and psychologists, have worked on the issues of health and illness, and, thus, the anthropology and sociology of health and illness are still considered new fields. As I noted in Chapter 2, social scientists mostly focus on demographic issues, health policies and how the health issues are covered in the media, rather than on illness narratives, and they rarely have a micro perspective. However, I believe that social scientists should focus more on the illness narratives in order to understand how the patients experience and evaluate health and illness. The patients' perspectives are the least recognized items in the debates on the health problems in Turkey, and that makes those debates rather one-sided and inadequate. Social and health scientists should also develop a cross-cultural perspective on the illness narratives, by studying accounts of illness narratives in other societies. By doing that, they can compare the Turkish health conditions with the other countries' in terms of how particular biomedical discourses and ideologies influence the patients' illness experiences. Such studies will give Turkish scholars valuable clues about how the patients' illness narratives can be better incorporated in the health realm, by shaping the social and medical conceptions of cancer and cancer patients. The inclusion of the patients' voices would help to create a more pluralistic and inclusive biomedicine. Health care providers would be also more tolerant of the ways people benefit from the alternative or complementary healing, and appreciate the social, cultural and psychological factors which lead them to do so.

“Local” studies on what the patients experience in the health realm in different societies and how they construct and share their illness narratives would also help to reformulate the often abstract and general statements on global health issues, such as the statements of the World Health Organization (WHO). The social and cultural

conceptions of health and illness(es) and the patients' expectations from the health care providers influences how the right to health is interpreted and negotiated in different societies. The question here is not that some societies have to accept a lower quality of health care, or some patients have to be socially and economically discriminated against, but how to fill the gap between the general statements about the whole of humanity, and the particular, local conditions, which shape the health delivery in different societies.

This issue is especially true of the WHO statement about integrating the complementary and alternative health systems to biomedicine both at discursive and institutional levels. As Christopher Dole (2004) explains, the modernist view of popular Islamic health prevents such integration in Turkey, to the extent that many health care providers hardly tolerate patients who speak about religious healing practices while in the hospital. Many health care providers consider that the "Islamist" patients, whom they claim to recognize by the veil in women and the beard in men, would give priority to their religious healing practices and home remedies, even while receiving their medical treatment. However, I found that the cancer patients who claimed to be religious argued that it is normal for them to benefit from both the medical and religious health practices, since they see those practices as complementary, rather than alternative. Those patients view modern medicine as the most effective biological treatment, and "traditional," Islamic medicine, as providing communal and psychological support which helps them to feel better. Similarly, they wish that Turkish modernity could be more inclusive and tolerant toward religious views and practices, in how they are played out in health care and in everyday social interactions.

**A Possible Agenda for Future Research:** As I mentioned in the Chapter 3, cancer patients increasingly form small support groups from neighbors and other patients who are not from their family or immediate community. This can be related to the current weakening family and community ties because of migration and the increase in the career opportunities for the young and the educated. The patients thus turn to other cancer patients for the help and support that they need, especially in terms of sharing their illness narratives. In that context, the organizations which are founded by the cancer patients become crucial in providing economic, bureaucratic, social and psychological help. During my fieldwork, I came across several such organizations, founded in the 2000s in the big cities, such as İstanbul, Ankara and Bursa, which received the active support of several health care providers. I briefly visited several of them in Istanbul and Ankara, but my focus on cancer patients' illness narratives, and the social and medical conceptions of cancer prevented me from a detailed study. These organizations differ from each other in terms of their official status, the number of patients who benefit, their affiliation with particular hospitals or faculties of medicine, and their social visibility.

Most of these organizations are exclusively for female breast cancer patients, and are funded by large-scale, international firms, such as Avon. The popular association of breast cancer with genetic susceptibility, which largely prevents blaming the patients for their cancer, in contrast to the lung cancer patients who are heavy smokers, views those women as innocent victims, which may be the major reason for more corporate and organized attention for them. The corporate firms tend to choose the “neediest cases” for their charity projects, and prefer to target people who suffer from external conditions for which they are not responsible, such as earthquake survivors and breast cancer patients. The effectiveness of early diagnosis in treating breast cancer has also led to large-scale

projects on breast cancer awareness, and the effect of breast cancer on the women's sexuality and personal interactions draws the attention of other women, including the feminist groups. Some of the breast cancer patients' support groups are formed and operated through the internet, mostly among middle or upper class, urban and professional women, who also derive the benefit.

Organizations for cancer patients mostly reach the middle or upper classes, and urban patients who actively participate in public life. Therefore, they are inadequate in reaching out the large number of "other patients" with disadvantaged socio-economic backgrounds or who have limited access to public life, such as elderly housewives or recent migrants. For a possible future research project, I aim at investigating several of those organizations, focusing on who founded them and why, who participates and benefits, what kind of support they provide, and how the patients evaluate them. I will investigate whether the organizations have the potential of providing a much-needed social platform where the patients, health and social scientists, health care providers, politicians, journalists and activists can come together and discuss relevant issues.

I will study the possible ways through which the organizations can reach out to a larger number of patients from various socio-economic backgrounds, and how they can cooperate with the media and medical, political and social organizations. I will also investigate the ways in which the organizations acknowledge and further existing family and community support for the patients. Finally, a comparison of such organizations with the similar ones in different countries, such as the United States, where they are very active, would provide valuable information about how different forms of health care influence the activities and structures of such organizations.

A second possible research project I would like to pursue is to collect the illness narratives of Turkish patients about another major illness, such as Tuberculosis or AIDS, and compare these with the cancer narratives in terms of the patterns of discrimination and marginalization. In addition, are the social and medical conceptions of those other illnesses similar or different from the conceptions about cancer? Can patients with a different illness be compared in terms of the ways in which they cope with the physiological, psychological and social problems? What kind of problems do these patients experience in constructing and sharing their illness narratives? These initial questions would guide me in studying the narratives of other illnesses in order to compare them with cancer narratives.

Finally, re-visiting the same topic around 2010, when the current government's health reform will be fully implemented, may be a worth-while project to pursue, since the reform, which has only been locally and partially applied since 2003, aims at reducing the economic inequalities in access to health care and improving bureaucratic procedures. The reformers recognize that every citizen has a right to health and have started to regulate the medical system so that everyone with state-insurance can gradually benefit from the private hospitals. So far, in mid-2007, only particular sections of some private hospitals have started to accept such patients, and the major aspect of the reform are still being debated among the health scientists and health care providers. The reformers claim that this will result in less crowds, less anonymity, and a less inhibiting bureaucracy in the state hospitals, and will also improve the interactions between the patients and health care providers. How will the reform influence the patients' experiences in the health realm, especially their interactions with the health care providers? What will the patients with disadvantaged socio-economic backgrounds experience in the private hospitals?

Comparing the cancer narratives of 2010 and 2003 would also help me to understand the interactions between large-scale social policies and experiences of individual patients.

Once the characteristics of the health reform are definite, and the reform fully implemented in the country, cancer patients would possibly deal with a new set of problems and questions, as well as enjoy new rights. In the 2000s, cancer and cancer patients are more visible in society, and the medical authority is being challenged by scholars, journalists, social scientists and “lay people.” The reforms will hopefully be informed by those changes and lead to a more pluralistic social and medical conception of cancer, with patients playing an active role in shaping them. Of course, this rather optimistic view will make sense only when cancer patients from different socio-economic backgrounds find access to various social platforms where they can share their illness narratives, and when the taboos around cancer and cancer patients are challenged, not reproduced. The increase in the efficacy in diagnosing and the treatment of cancer will also play an important role in that process, since that could challenge the persistent association between cancer and death. As Turkish society becomes more aware of various cancer narratives, which reflect the social and cultural diversity in Turkey, cancer could become an issue that can be openly discussed with all its complex public, private and personal aspects. The people with cancer could then be perceived first as human beings, with their own thoughts and emotions, working to survive and to gain a sense of control over their illness, rather than being viewed as “patients” to be separated from healthy people.



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