QUESTIONING EFFECTS OF PATIENT EMPOWERMENT ANTECEDENT BY INFORMATION AND COMMUNICATION TECHNOLOGIES IN BREAST CANCER PATIENTS: A CASE STUDY FROM TURKEY

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ABSTRACT

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This thesis aims to examine how patient empowerment based on Internet information has impact on health care processes and patient – physician relationship. The process of empowerment is analyzed in three main steps; searching and obtaining information; sharing and discussing obtained information with providers; and involving decision making process. Study domain covers with breast cancer patients continuing their treatment in hospitals. In-depth interview methodology has been employed. Interviews are conducted in two settings: one is a university hospital; other is a state hospital of Ministry of Health. Sample size was 20 patients and 6 doctors. As result of study we observed that most of the breast cancer patients have low level of empowerment. This is mainly caused by perception of cancer and high level of anxiety of patients. Most of the middle class women even though they use Internet in everyday life, they neither want to search for information on their cancer not they want to involve in decision making.. Some of the educated upper middle class use Internet however they do not share gathered information with their doctors. They mainly use this information to test competency of doctor. Most patients prefer to seek for information until they made a decision, mostly finding a trustable doctor. Even though some of upper middle class, high education women use Internet intensively, they do not involve in decision and leave the responsibility to the doctor. Young generation regardless of their socio economic situation has tendency to use internet and getting empowered.

Keywords: Patient Empowerment, Breast Cancer, Internet, Doctor Patient Relations

ÖZ

MEME KANSERİ HASTALARINDA BİLGİ TEKNOLOJİLERİ İLE GÜÇLENDİRİLMİŞ HASTA MODELİNİN ETKİLERİNİN SORGULANMASI: TÜRKIYE'DEN BİR ÖRNEK

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Bu tezin amacı Internetten elde edilen bilgi ile güçlenen hastanın sağlık bakım süreçleri ve hasta doktor ilişkisindeki etkilerini araştırmaktır. Güçlendirme süreci üç ayrı aşamda incelenmiştir: bilgiyi aramak ve elde etmek, elde edilen bilgiyi sağlık personeli ile paylaşmak ve tartışmak; karar süreçlerine katılmak. Çalışma kapsamı hastanelerde tedavileri süren meme kanser hastaları olarak belirlendi. Mülakat yöntemi uygulandı. Mülakatlar birisi üniversite hastanesi, diğeri Sağlık Bakanlığına bağlı devlet hastanesi olmak üzere iki ayrı ortamda uygulandı. Örneklem büyüklüğü 20 hasta ve 6 doktordan oluştu. Bu çalışmanın sonunda meme kanseri hastalarının güçlenme düzeylerinin düşük olduğu gözlemlendi. Bunun temel nedeni kanser algısı ve bunun hastalarda yarattığı yüksek düzeyde endişe olarak belirlendi. Orta sınıftan gelen birçok kadın günlük hayatlarında Interneti kullanırken, hastalıkları hakkında bilgi araştırmak ve karar süreçlerine dahil olmak istememekte. Bazı eğitimli orta üst sınıftan gelen kadınlar Interneti bilgi toplamak amacı ile kullanmakta ancak bu bilgileri doktorları ile paylaşmamakta. Elde ettikleri bilgiyi genelde doktorlarının yeterliliğini sınamak için kullanmakta. Birçok hasta bilgi edinme sürecini bir karara varana, genelde güvendikleri bir doktor bulana kadar sürdürmekte. Bazı orta üst gelir gurubu kadınları Interneti yoğun olarak kullansada, karar süreçlerine dahil olmak istememekte, sorumluluğu doktora bırakmakta. Genç nesilin sosyo ekonomik statüsü ne olursa olsun Interneti kullanma ve bilgi ile güçlenmek eğiliminde olduğu sonucuna varılmıştır.

Anahtar Kelimeler: Güçlendirilmiş Hasta, Meme Kanseri, Internet, Hasta Doktor İlişkileri

To My Husband

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TABLE OF CONTENTS

CHAPTERS

APPENDICES

LIST OF TABLES

TABLES

LIST OF FIGURES

FIGURES

CHAPTER 1

INTRODUCTION

This thesis aims to examine how patient empowerment based on Internet information has impact on health care processes and patient – physician relationship.

Patient empowerment has been emerging as a new aspect of health care delivery in recent decades. Many countries carries health system reforms, these reforms emphasize empowered patient as a partner in the new form of health care delivery. This research examines patient empowerment as a new aspect of the health care demand and supply, and aim to identify how this new aspect of health care delivery influences patient physician relationship in Turkey.

The process of patient empowerment has four key processes, namely (1) information sharing, (2) doctor-patient communication, (3) shared decision making, and (4) patient self-care. In our research we will undertake first three processes. Patient self care process is related with the chronic diseases and long term care. However our study domain is limited with breast cancer patients. Cancer as a disease can not be cured or state of health can not be improved with patient self care. Therefore we are excluding patient self care process in our study.

Although health care information can be shared in many forms, this research limits itself only information and communication technologies namely Internet source. There are huge literature on how Internet became a source of information in health care and concept of internet informed patients. This thesis, undertakes internet informed patient as empowered patient and examines changing patient physician relationship based on this empowerment.

This research also examines patient empowerment impacts on changing nature of health care delivery process. Patient empowerment becomes a challenge to patient-physician relationship asymmetry. Health care in its nature is proxy demand and there is an imbalance power relationship in favor of provider side. Internet informed patient appears as a way to level the hierarchal relationships that exist between patient and provider. In our research we will analyze changing aspects power asymmetry related with patient empowerment.

Additionally, related with patient empowerment we will analyze changing nature of physician patient communication, whether patient – physician encounter is transformed to mutual participation, or whether internet informed patient cause demanding encounter or consumer shopping type of behavior.

Lastly we will examine relation of patient empowerment with consumerism. We will question whether patient or physician perceives patient empowerment related with the Internet as a source of purchasing better health care.

Research domain has been limited with breast cancer patients as demand side and hospitals as supply side. We will cover three different type of health care provider. Each provider type has intrinsic properties, and we expect that physician will follow different patterns against the patient empowerment. First provider type will be one of the cutting edge care giver in Turkey, specialized both in education and provides tertiary levels of services, with highly connected with developments in outside of world. Second provider type will be a typology of ministry of health hospital's oriented only treatment processes. In this research we have stated following hypothesis related with our research questions:

- How perception of disease and coping mechanism has impact on patient empowerment?
- Does patients are willing to obtain information?
- How do patients use information in their health care related decisions?
- What are the perceptions of good health care delivery?
- What are the roles of family during health care processes?
- Which sources patients used as source of information?
- How computer literacy and access of internet effect on empowerment?
- How patients and physicians perceive reliability of internet information?
- What are the main usage typologies of internet by patients?
- How patients perceive the effects of internet information in their care process?
- Does internet usage impact on the level of empowerment?

CHAPTER 2

LITERATURE SURVEY

2.1 Changing and challenging era

Today, globalization or ‘growing interdependence’ between different peoples, regions and countries in the world is the term used to describe social and economic relationships that extend worldwide. Diffusion of communication and media across the globe created a ‘global village’.[1]. In the second half of the twentieth century, economical and socio-cultural globalization and information technologies, affected health care systems with respect to many perspectives as the other societal systems (Fig.1). Biomedical therapeutics, the medical profession, and the relationship among doctors, patients, and the public have been totally changing. [2]

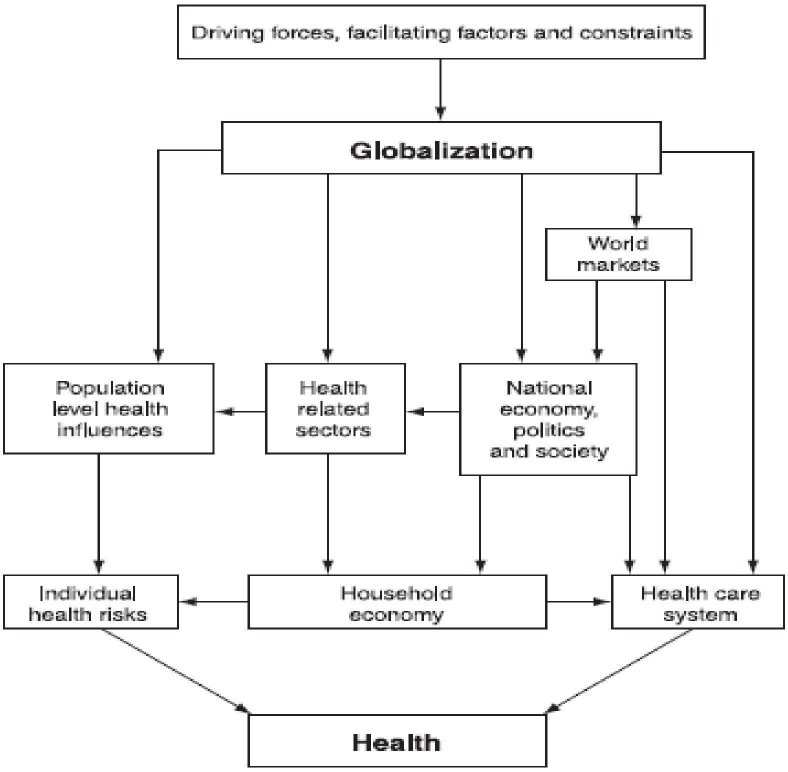

Figure 1. Outline conceptual framework for globalization and health

Source: Public Health for the 21st Century, New Perspectives On Policy, Participation And Practice, 2nd edition, Editors: Judy Orme, Jane Powell, Pat Taylor, and Melanie Grey, 12, Stuart McClean, Globalization and health

The patient-physician- relationship, the basic relationship of medical care, is structural asymmetric. The unequal division of knowledge and instrumental abilities, the one dimensional professional and social competence until the application of sanctions, provides the social position of a physician with power. Drivers of the emerging age force to transform this critical relationship dramatically.

2.2 Profession, professionalism and power

To understand the patient-physician- relationship, firstly association between medical professions, power, and empowerment must be studied.

Profession is a form of occupational closure in which a group is allowed by the state to administer its own members. In the history of medicine the medical profession has gone through three stages. Under a patronage system in the eighteenth century the patient had power over the doctor; with the rise of the hospital in the nineteenth and twentieth centuries the profession exercised collegial control over its members; with the rise of laboratory medicine the profession's power is mediated by the state [3].

Professionalism is the characteristics of an occupation held to discriminate it from other occupations in the division of labour that are oriented to the profit motive. As identified by Talcott Parsons in his analysis of medical practitioners, these characteristics are universalism, neutrality about the condition under treatment, an orientation towards the collective good and the delivery of the best technical and scientific service available, independent of the patients' social characteristics.[3] Professionalism can be defined for all time as the means by which individual doctors complete the medical profession's contract with society. [4]

Within the sociology of health, medicine has most often been viewed as being the core part in a network of relationships in which the profession both generates power over other groups or institutions and reflects or is shaped by external factors and forces. [5]

Medicine has often been used as an analytical example to advance theories of the professions because medicine is assumed to be the epitome of what “profession” means. Explanations for medical power are tied to theories of the professions in general. There is a conventional history of analysis of the professions that moves from Carr-Saunders and Wilson (1993) through Wilensky (1964) and Parsons (1951, 1964) to Johnson (1972) and Freidson (1970), to Larson (1977, 1980), Navarro (1976, 1986) and McKinlay and Arches (1985), to Foucault (1973, 1976), Witz (1992) and the postmodernists. This sequence can be described in terms of a change from trait theories to functionalist theories to neo-Weberian or neo-Marxist “power” theories. Most recently have come challenges to power theories, particularly from feminism and from Foucault. [5]

The Professional 'traits' model is a normative model which focuses upon the 'ideal type' characteristics of a profession. The socially functional 'traits' approach is informed by Durkheim's notion of professional ethics i.e altruism & objectivity. The 'Power' approach is an 'action-orientated' analysis of the professions. The key concepts include autonomy & dominance (Friedson), and the 'Professional closure' strategy. The long-term refuse in the influence and power of the medical profession in the health services (and the rise of managerialism) has been much debated. In the 1970s medical sociology was strongly influenced by Eliot Freidson’s thesis on the medical profession. This held that in the USA and in other advanced health care systems the medical profession held sway. According to Freidson’s approach to the professions it was the degree of autonomy over work practices that provided the basis of medical power. This independence from examination or regulation was then used and extended beyond the borders of medical practice. In so far as the medical profession made claims to have influence over wide areas of life and over the forms and delivery of medical treatment, they were acting, according to Freidson, essentially on a moral terrain. Health, illness and health care were seen as issues being decided by the medical profession alone, divorced from lay perspectives. [6]

Freidson shows that there exists a knowledge gap between doctor and patient, which gives the doctor a strong position. This position grows even stronger as medical technology evolves. Even when the patient, for instance through the Internet, becomes more knowledgeable, the information is highly technical and difficult for the patient to interpret without help from the physician. [7]

2.3 Scattered Professionalism and New World Order

The rise of a modern professionalism literature within medicine can be traced to the 1980s and 1990s with the emergence of what has been termed ‘‘nostalgic professionalism.’’ This particular discourse emerged from a consensus among medical leaders that medicine had strayed from its ‘‘traditional commitments’’ to patient welfare and had violated its social contract with society. In response, organized medicine embarked on a collective ‘‘professionalism project.’’ [4]

In an afterword to the second edition of “Profession of Medicine”, Freidson noted changes in health care organisation that had occurred since his first edition, which, he said covered the ‘Golden Age’ of medicine between 1945 and 1965. In particular, the rise of Medicare and Medicaid in the USA, which provided state involvement in ‘paying the bills of the elderly and the poor’, and of ‘large corporate employers’ paying for medical insurance, moved the centre of gravity away from the medical profession. Freidson maintained that ‘the loss of extensive political influence and economic independence does not represent the loss of professionalism as I have described it’. While the loss of ‘clinical freedom’ was ‘virtually complete’, Freidson could see that all kinds of informal moves by the profession to evade constraints and maintain a high degree of control were always possible. [6]

Across a broad number of initiatives, medicine began to develop definitions, assessment tools, standards/competencies, and curricula. It also identified ‘‘market forces’’ and ‘‘market incentives’’ as the primary threat to professionalism. Version of professionalism includes altruism, respect, honesty, integrity, dutifulness, honor, excellence, and accountability, is now moribund. [4]

A crucial aspect of many views of medical power is the role played by knowledge. [5] Medicine and healthcare face fundamental changes in the contemporary era. Within the advanced capitalist countries came the rise of neo-liberalism. The rise of neo-liberalism on a worldwide basis has produced a number of trains on the medical profession. On the one hand has come increasing public and private institutional pressure towards the rationalization of care. On the other there are rather ambiguous relationships between medicine and currently dominant neo-liberal governments and ideologies. [5]

The challenges to the medical profession within health care systems come from a range of sources - rationalisation, managerialism, consumerism and the breakdown of professional boundaries. [8]

There are other factors which point to a more radical shift in the role of the medical profession in the health services. Partly in debate with Freidson, McKinlay and Marceau for example, have argued that the external context of medical practice marks a major break with the past. Most notably, they argue that ‘medical dominance’ has given way to ‘corporate dominance’. Where once fee-for-service held sway in the US system, “increasingly concentrated and globalized financial and industrial interests” dominate. These interests not only influence the financing of health care but the way health care organisations are run and medicine practiced. [8]

McKinlay and Marceau make two other points that are relevant to the discussion here. One of these concerns an additional feature of the ‘external’ environment; the increasingly globalized character of health care. In the USA and in the UK the movement of medical personnel across national boundaries is becoming increasingly common. The European Union, for example, is providing increasing opportunities for mobility for doctors between countries, subject to local licensing and training requirements. Additionally, globalization also means that health care corporations can operate on an increasingly international basis. The second point made by McKinlay and Marceau concerns the increasing competition among health care workers. [8]

From the foregoing discussion it is possible to see important processes at work in the ‘new’ forms of health care organisation appearing in countries. Most importantly, perhaps, the role of the medical profession is being transformed by the rise in bureaucratic and corporate pressures. [6]

In the article ‘‘The end of the golden age of doctoring’’ the authors argue that different social influences have even led to an erosion and decline of the medical profession. The most important reason for this, according to the authors, lies in the shifting agenda of the national and local state. Earlier, the state served as a guardian for the medical profession by its legitimatizing function for many professional activities and by ensuring the profession’s profit through different payment systems. Nowadays, the state is more reluctant to intervene in economic and social life, as well as in medical care. This means that the state is neither willing to be in charge of the medical healthcare sector, nor willing to protect the medical professional core in the same way that it used to do. Instead, the state has laid its’ efforts on advancing the interests of the financial and profit-seeking providers in the healthcare system with the aim of stimulating the private market place. [7]

Health sectors around the world are being restructured in ways that fundamentally affect the nature of professionalism. While the case for change is apparent on financial and technical grounds, there are strong suggestions that many of the reform initiatives have failed to achieve their objectives. There are also widespread reports of unease and alienation amongst many within health services, especially clinical professionals, and there are discussions of "deprofessionalisation". [9]

2.4 Patient Empowerment as a Part of Health Reforms

Health system reforms are being driven by attempts to meet ever increasing health service demands in the face of cost containment pressures. There is little agreement concerning the preferred features of health funding models. A micro-economic framework is used to define universal performance characteristics for optimal health funding arrangements. Two principle requirements emerge. These are demand side reform to empower consumers and supply side reform, to promote opportunities and incentives for a responsive service system and competition amongst providers. [10]

Countries are suffering from rising cost of health care. Most of the countries are spending their 7 to 9 percent of GDP to health. Hence these situations are unsustainable almost all countries are conducting health reforms in order to diminish rising costs. Aging society, chronic diseases, expensive diagnostic technologies, and rising expectations are listed as the main reasons for high spending. Therefore new concepts are introduce to support staying healthy, managing chronic disease with lower costs, and coping aging society with home care. For decreasing costs provision of care distributed from acute care hospitals to personal health maintenance programs.

Patient empowerment is closely related with the health policies of countries. UK defines empowerment as expert patient [11]. Expert patient concept mentions those who can manage their own illness and conditions by developing knowledge related to maintaining health and countering illness. Empowered patient concept has become part of national health care delivery system in US with the Sen. DeMint’s Proposal for Patient Empowerment Health Care Plan in this summer (know as Obama’s health reform).

Health reforms changes health care market and nature of health care demand. Proxy nature of health care demand changes with patient empowerment and new market with new personal products is formed.

2.5 What is patient empowerment?

Empowerment is supported in the health literature, not for reasons of economic efficiency, but because it improves health outcomes (psychological empowerment is a valued health outcome in itself) and as an ethical position. There is a growing body of evidence concerning the impact of individual behaviour and of the sense of control over ones life, on health and well-being. Life style has a profound influence on the incidence and progression of common diseases such as coronary heart disease, stroke, diabetes and cancer. There is evidence concerning the role of social support in disease progression and outcomes in diverse areas such as cancers, chronic pain management, weight loss and heart disease. Whether or not consumers consciously seek to assume responsibility for their own health, their actions and the nature of the communities in which they live, do influence their health outcomes. Where consumers are supported and encouraged to assume responsibility for their own health and to take a greater role in decisions about their own health care (and/or that of their families), enhancement of well-being is observed. This can be attributed to the enhanced sense of control, to improved self-care practices and to changes in the mix of health services utilized. Evidence of the capacity to empower consumers and the potential influence on health outcomes, derives from a range of health problems, covering both chronic and acute settings. However, few trials are established specifically to explore this issue and thus, much of the evidence is indirect. An introduction to a portion of this literature is provided below. It covers programs designed to enhance consumer involvement in decisions about their own health care and the adoption of specific behaviors to enhance self-care. It also includes reference to the literature on powerlessness as a determinant of health status. [10]

Holmstrom and Röing cites a definition of patient empowerment from Feste and Anderson as follows ‘‘The empowerment philosophy is based on the assumption that to be healthy, people must be able to bring about changes, not only in their personal behaviour, but also in their social situations and the organizations that influence their lives’’. They also give list of characteristics or attributes of patient empowerment from Rodwell as follows ‘‘a helping process, a partnership which values self and others, mutual decision making using resources, opportunities and authority, and freedom to make choices and accept responsibility’’ [12].

As Aujoulat mentions patient empowerment emerge as an alternative to compliance in the health care provider patient relationship. In compliance oriented approach patients are the recipients of medical decisions and prescriptions, whereas in the empowerment-oriented approach views patients as being responsible for their choices and the consequences of their choices. As Aujoulat cite from Steele et al., patient empowerment might be defined as a process of behavior change, with a focus on how to help patients become more knowledgeable and take control over their bodies, disease and treatment. In this definition, empowerment is viewed as a process of ‘‘activating’’ patients, who as a result of ‘‘rejecting the passivity of sick role behavior and assuming responsibility for their care (.) are more knowledgeable about, satisfied with, and committed to their treatment regimens’’. However in their studies

Aujoulat et al. argues that this definition of empowerment is a professional construction, it is built on the assumption that patients most value being in control of medical decisions and management of treatment, it ignores some underlying factors of the decision-making capacity, which are linked to important dimensions of the patients' illness experience, such as their need for security, self-determination, and a continuous sense of self. As their study result that empowerment and control are not the same things, in some cases, empowerment may be an indicator that the patient is avoiding awareness of the impact of illness on his/her life [13].

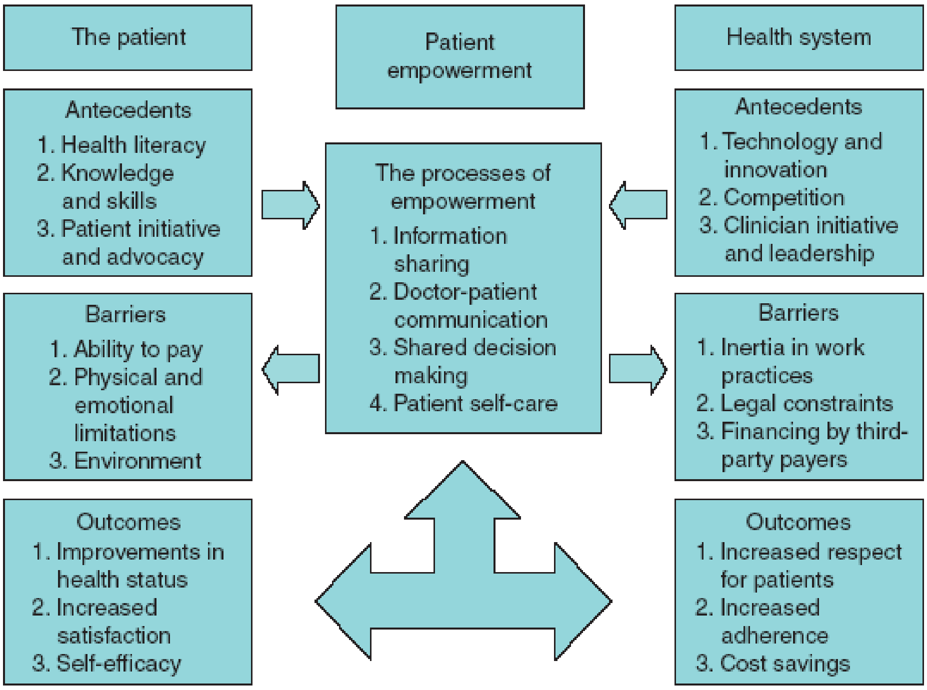

Figure 2.: Patient empowerment as a partnership between patient and health system.

Source: Bridges J F P, Loukanova, S., Carrera, P. (2008). Patient Empowerment in Health Care, In International Encyclopedia of Public Health, Editor-in-Chief: Heggenhougen, K. ISBN: 978-0-12-373960-5.

2.6 Information Technologies and Patient Empowerment

Another critical factor on the erosion of the medical profession is believed to be the new information technology that offers an opportunity to empower patients. Computerized information systems with records of various aspects of the clinical encounter make it easier for the patient to compare different providers in terms of quality of care, patient satisfaction and productivity. This might lead to a feeling of powerlessness among physicians and implies that they, intentionally or unintentionally, oppose policies that empower patients. [7]

In the context of health service delivery, deprofessionalization denotes a trend towards a demystification of medical expertise and increasing lay scepticism about health professionals, suggesting a decline in the power and status of the medical profession.This process has been linked to increasing consumerism, the rise of complementary medicine and the emergence of the Internet. Knowledge previously excluded health from public scrutiny is being disseminated, and can, it has been argued; potentially disrupt the expert status of, and professional autonomy of, the biomedical community. As well as the potential for paradigmatic challenge, inspired by Internet-sourced knowledge, the very act of the patient seeking such information independent of the expert contests the traditional biomedical assumption of the patient as recipient of knowledge and expertise. Despite considerable speculation about the impact of the Internet for the medical profession, no data exist on how specialists view, and are responding to, the Internet-informed patient within the context of the medical consultation. [15]

Over the past 4 decades, patients have expressed a desire to participate more in decisions regarding their health and health care. Although the precise role that a patient wishes to play in decision-making varies, the desire for medical information remains high and is increasing. This mounting public interest in health information arises from an interaction among many current societal, economic, technological, scientific, and governmental trends. The social changes related to consumer rights and women's health movements of the 1960s and 1970s have had a significant impact in "empowering" health care consumers in North America. The technological advances of electronic media have fed this wave of medical information consumerism, as health care and health education has become less constrained. [16]

As empowerment is central theme for health reforms, information technologies is the main resource for this change.

> *"Personal empowerment has raised important issues for health policy. The plurality of the health information now available and the emergence of new producers of health information has led to structural changes in the process of diffusion and appropriation of health knowledge. Clearly the Internet is a central vector of these structural changes" [17]*

Lemire et al. states that there are three logics of personal empowerment through health information found on the Internet. According to their results development of feelings of competence and control are structured around three different empowerment logics: professional, consumer and community. This implies three types of aptitudes fostered when the Internet is used: to do exactly what is prescribed, to make choices on the basis of one's own judgment, and to become freer through mutual assistance in a "virtual" community.

Patient will informed by using information technologies such as web sites, online support groups, electronic libraries such as NHS Direct Online, etc. As Fox cites concerns remain over the reliability and validity of web-based information, and as part of the development of an 'expert patient culture', organizations such as the ABPI and the World Health Organisation (WHO) have developed print and web-based guidelines on how to interpret, assess and use web-based information. Furthermore, the ABPI provide a public link from their website to the Electronic Medicines Compendium EMC), which provides a guide to available prescription medicines in the UK. [18]

Pandey defines three different model for explaining use of Internet for health information namely: health and wellness model, health needs model and search cost model. In the first model, called the health and wellness model, posits that women who are health-conscious view and use internet as yet another mechanism to pursue good health. The second model, called the health needs model, puts forth the idea that use of internet for health information is triggered by a health condition. The third model, called the search costs model, argues that internet use for health information is viewed as a means for cutting down on information search costs entailed in the use of alternate modalities [19].

To people with the necessary technology the internet can provide vast amounts of health information. However, there are concerns about the quality of the information and how it may affect relationships between patients and doctors. Health information for patients was developing a higher profile before the use of the internet became widespread suggesting a quite remarkable change from the traditional ‘doctor knows best’ approach [20].

The Internet enables patients to inform themselves independently from physicians about health-related issues. In industrialized countries many patients use the Internet to obtain healthrelated information. Two North American studies showed that 50% of patients searched for health information on the Web, without showing any differences between subsamples. A Swiss survey demonstrated that 30% of patients who had access to the Internet used the Internet to obtain health-related information. Today physicians are faced with patients who use health-related Internet information (HRII) before or after the consultation. Consultations are likely to change in response to HRII and at least two scenarios are discussed: first, consultations with patients using HRII could become more controlled by the health professionals since they want to regain control over the situation. In this scenario physicians ignore patients’ HRII or determine its direction through ‘‘prescribing’’ websites favoured by themselves. The second scenario anticipates that consultations with Internet-informed patients involve a more patient-centred consultation in which the health professional and patient collaborate in a mutual manner. This scenario goes along with the assumption that the use of the Internet reflects a shift in the patients’ role from passive recipients to active consumers of health services: the Internet offers patients the opportunity ‘‘(. . .) to increase their [patients] knowledge, become more informed, and increase their involvement in their health care decision-making process”. [21]

Finally, Internet and ICT emerged as the practice of medicine was undergoing a crisis. On the one hand, biological and surgical techniques were developed and extensively used and, on the other hand, medicine was fragmented into numerous sub-specialties as medical knowledge improved. As a result, the costs of medical procedures increased considerably, the quality of patient physician relationships was tarnished and, in addition, iatrogenic risks were not and have not yet been fully controlled. Patient behaviors changed at the same time and the number of health-related information requests (made mainly on the Internet) increased. Caregivers are very much lagging behind patients in using the Web as a resource. The patients are now better informed and self-managing; they want to be part of the health decision process and are increasingly requesting access to the data contained in their medical records. Medical practices are questioned every day and increasingly leading to legal actions that were unheard of in the past. Overall, those changes are inducing a standardization of medical procedures with quality assurance as well as medical/economical evaluation and accreditation requested by governments and implemented by administrative and financial services. [22].

2.7 Transforming Patient Physician Relationship

The political discourse known as 'neo-liberalism' which has dominated the public policy debate over the past two decades emphasises the role of the market in facilitating individual choice and the responsibilities that go with that freedom. Its political-ideological goal is to 'de-regulate' the traditional top-down role of the state in the provision of health and welfare services [8].

This neo-liberal political perspective is underpinned by the assumptions of what is known as 'rational' or 'public choice theory'. This position argues that social life is essentially made up of solitary, self-interested individuals who must by force of circumstance make rational choices after weighing all the possible alternatives. Therefore, every individual must be given the opportunity to manage and take responsibility for the inherent risks in their life - citizens as agents of their own government. It contains an essentially implicit moral message about individual responsibility and worth [8].

As the traditional paternalistic model of medical decision-making, in which doctors make decisions on behalf of their patients, came be seen as outdated largely as a consequence of these new ideas around governance, so the role of the patient in the consultation began to be reformulated in terms of the new 'patient-centred' strategies. [8]

Successful physician–patient communication about decision making plays a critical role in healthcare delivery, yet there are conflicting messages about changing roles for physicians and patients. A mandatory role for patients as autonomous decision makers has recently been recommended, since patients alone weather the consequences of their medical care. However, others advocate that patients be allowed to participate to the extent they desire, completely delegating decisions to their physicians if they so choose. The model of patient participation where both physician and patient communicate information and values and make decisions together—called shared decision making—has been embraced in literature and the Institute of Medicine has recommended including it in medical school curricula as a mechanism to improve care.

Patient-centred medicine stresses the importance of understanding patients' experiences of their illness and any relevant social and psychological factors. 'Shared decision-making' has a number of similarities with patient-centred medicine. However, the concept also includes patients' active involvement in the treatment decision. The 'Shared decision-making' model has four main characteristics.

- both the patient and the doctor are involved
- both parties share information
- both parties take steps to build a consensus about the preferred treatment

an agreement is reached on the treatment to implement. [8]

Roter categorizes nature of doctor patient relationship based on variety of power relations. She suggests that if doctor has high power and patient has low power form of relation is paternalism. In paternalism goals and agenda set by the doctor, patient values only assumed and physician role is guardian. If both part has high power relation become characteristic become mutuality. Goals and agenda set by negotiation, patient values are jointly examined, and doctor act as an advisor. If patient has high power and doctor has low power, form of relation turn to consumerism. In these situations goals and agenda set by the patient, patient values are unexamined, and doctor turns to a technical consultant. If both part has low power relation becomes unclear. [23]

Yet there has been little discussion resolving the potential conflict between promoting shared decision making as ideal and accommodating individual patient preferences for participation (or lack of participation) in decision making. There is evidence that not all components of the shared decision making model are equally desired by patients. Early work in this area identified two distinct components of patient participation: information exchange and decision making. Later work further refined the components to three: information exchange, deliberation, and decisional control. It is well established that patients want to receive information from their physicians almost universally, but less is known about information transmission, i.e., patient preferences for providing information to their physicians. Preferences for deliberation (i.e., formal discussion about options) and preferences for decisional control (i.e., power over the final selection of treatment) are known to differ substantially among patients, although it is unclear whether patients who prefer discussing treatment options also prefer making the final decision about treatment. Where one study suggests that patients do not want to be involved in problem-solving tasks while retaining control over decisions, others advise patient involvement in both stages. Often the concept of deliberation as distinct from decisional control is ignored entirely.

Consequently, there is little information available to assist clinicians in understanding and distinguishing the different roles patients prefer in the decision making process. Distinguishing these roles is an essential step towards promoting patient-centered care, care that respects and responds to individual patients' preferences. Physicians have been classified according to their attitudes about paternalism, patient autonomy, and deliberation, but patients have not been similarly characterized according to their preferences for participation in multiple, distinct stages of healthcare decision making [25]

As Fox at al cites [18], such moves will transform the doctor–patient relationship from a ‘professional led’ interaction to a ‘doctor–patient partnership’, in which expert patients ensure that treatments are appropriate to their individual needs. (Note: We should distinguish these individual needs from the concept of responsiveness. Whereas responsiveness covers non medical preferences of patient where as patient empowerment related with involving decision.)

Fox argues that empowered patient’ can be perceived as desirable, enabling the democratisation of healthcare, it can also be constraining. Patient might experience a tension between self reliance and compliance [18]. From the point of provider side such patient have been met with scepticism and some anxiety by health professionals, who fear more, rather than less, time will be needed to manage these patients [24].

2.8 Cancer, Psychological Responses and Role of Social Support

Emotional responses to cancer include severe depression, grief, lack of control, personality change, anger and anxiety, and this can occur up to 20 per cent of cancer patients. It’s interesting that, at least with operable breast cancer, the emotional state of the sufferers appears to be unrelated to the type of surgery they have. More obvious predictors of emotional responses to cancer include previous psychiatric history, lack of social support, age and lack of intimate relationship. With advanced cancer, the patient’s psychological health was closely related to their physical health. In addition to emotional responses to cancer, cognitive responses suggest that having a “fighting sprit is negatively correlated to anxiety and depression.

Taylor’s study of how woman with breast cancer coped with their situation showed three effective strategies. First, they engaged in a search for meaning of how they came to develop cancer (ranging from hereditary factors to stress). Second, they developed a sense of mastery over their illness by believing that they could control it (and any relapses) Finally they began a process of self enhancement in which they used social comparison with significant others in their lives to analyse their own condition. They showed “downward social comparison” by comparing themselves with people who were worse off than they were, thus enhancing self esteem and improving their own beliefs about their situation. Taylor's "theory of cognitive adaptation" thus involves a combination of meaning, mastery, and self enhancement in producing effective coping strategies for illness. [26]

Group living is perhaps the most significant adaptation of human beings. This tendency to come together is especially great under threat. Following the September 11 terrorist attacks, some of the most common methods people reported using to cope with this threatening event involved turning to others, including family, friends, and even strangers. There are tangible benefits to social affiliation under threat. For example, following a disaster, such as a fire, a flood, or a bombing, the presence of many hands can locate survivors and get them to safety. But the presence of others has long been known to foster adjustment to threatening events in other ways, specifically by protecting against adverse changes in mental and physical health that may otherwise occur in response to stress. Social support is defined as the perception or experience that one is loved and cared for by others, esteemed and valued, and part of a social network of mutual assistance and obligations. Social support may come from a partner, relatives, friends, coworkers, social and community ties, and even a devoted pet. Some of these are family support interventions. For example, when a person has been diagnosed with a chronic condition or illness, the family's participation in an intervention may be enlisted to improve the diagnosed patient's adjustment to the condition. In addition, involving the family in health behavior change programs may be beneficial for effective management of the disorder. Family support interventions may also be emotionally soothing to family members, in part by alleviating anxiety that may be generated by incomplete understanding or misinformation. Explaining exactly what the patient's condition is, what treatments will be needed, and how the family can help can mean that support provided by family members may be more forthcoming and effective. In addition, family members may receive guidance in well-intentioned actions that should nonetheless be avoided because they are experienced as aversive by patients. [27]

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For the most part, people who need help managing stressful events turn to their family, to friends, and to experts, such as medical caregivers, for the support they need in times of stress. In some cases, however, that support is not forthcoming. Family and friends may be ill equipped to provide the kind of support that a person needs for any of several reasons. Some conditions for which a person may require social support are stigmatized ones, such as HIV, cancer, or epilepsy, and stigmatized conditions can drive friends and family away [27].

2.9 Breast Cancer, Patient Empowerment and Internet

Pitts [28] examines personal web pages of women with breast cancer and explores the issue of empowerment in cyberspace. In her narrative analysis, she stated that :

> *"Gaining medical knowledge is also used as a way to level the hierarchal relationships that exist between patient, doctor and the medical industries. Indeed, current debates over the deprofessionalization of medicine address how users of the Internet gain lay knowledge of medicine and access health information for themselves, which may have the effect, as Hardey argues, of demystifying medical expertise (Hardey, 1999; see also Haug and Lavin, 1983). That medicine needs demystifying is an oft-repeated theme in these narratives, which repeatedly describe how the world of medicine can seem alien to laypersons."*

Author explores narratives to describe new aspects of dealing with medicine. She analyzes two different cases as follows:

> *"…While Dean puts this in the neutral terms of exploring a new culture, learning medical expertise is often described in these sites as part of an adversarial process. Some women, for instance, describe this process in terms of arming themselves with information as they try to negotiate the world of high-tech medicine. Their aim is not only to understand their cancers and choose the*

> *best treatments available, but also to demand that doctors share the power over their bodies and health care."*

The existence of the internet presents people with cancer with the possibility that they, (or their friends, relatives or professional or voluntary advisers) could gain a vast amount of information about their disease and its treatments. In a qualitative analysis of interviews with 175 people with cancers of the prostate, cervix, bowel, breast and testes we have described how they report using the internet to gather information about cancer, to help understand the diagnosis, to find out about treatments, to seek second opinions, to make decisions about treatments, to make anonymous enquiries, to find out about diet and complementary treatment approaches, to contact support groups and to campaign about cancer related issues. Most participants who had accessed the internet said that they had found it very helpful, although some described the information as potentially overwhelming in quantity, or overly focused on the health-care system. [20]

2.10 Cultural Model for Patient Empowerment

Individualism and collectivism are the dimensions of distinctions in the worldviews people use to construct and interpret social reality [29]. As Wagner argues individualism emphasizes the dignity of the individual and the sacredness of personal interests where as collectivism highlights the primacy of groups, in particular, ingroups whose members share one or more similarities and the eminence of shared objectives. In an individualistic worldview encourages social independence, individual autonomy, and personal quests, whereas in a collectivistic worldview encourages the construction of a social reality of close interdependence, enduring group membership, and attention to collective pursuits. These descriptions are end points of a line which has various middle points.

Chen and West emphasize that core element of collectivism is the perceived "oneness" with other people. They have mentioned three important facets of collectivism as follows: (1) consideration of the implications of one's decisions and actions for others. This facet reflects a person's tendency to think about how his or her behavior may affect the benefits and costs of others. (2) Sharing of each other's successes (3) Sharing of each other's failures. On the other hand, authors defined the major characteristic of individualism as the separateness of oneself from others. Again they have defined three elements for individualism: (1) Independence. This facet reflects an individual's value of autonomy in judgment, decision making, and actions. (2) Competitiveness. (3) Uniqueness [30].

Oyserman and friends states the plausible consequences of individualism and collectivism for psychology by respect to self-concept, well-being, attribution style, and relationality. When they examined individualism they defined that it implies three different facet, first with regard to selfconcept: "(a) creating and maintaining a positive sense of self is a basic human endeavor; (b) feeling good about oneself, personal success, and having many unique or distinctive personal attitudes and opinions are valued; and (c) abstract traits (as opposed to social, situational descriptors) are central to self-definition". Second with regard to well-being, "open emotional expression and attainment of one's personal goals are important sources of well-being and life satisfaction." Third, "individualism implies that judgment, reasoning, and causal inference are generally oriented toward the person rather than the situation or social context because the decontextualized self is assumed to be a stable, causal nexus." [31]. Authors also defines plausible consequence of collectivism from literature. Collectivism implies that first, with regard to the self, " (a) group membership is a central aspect of identity and (b) valued personal traits reflect the goals of collectivism, such as sacrifice for the common good and maintaining harmonious relationships with close others". Second, with regard to well-being and emotional expression, " (a) life satisfaction derives from successfully carrying out social roles and obligations and avoiding failures in these domains and (b) restraint in emotional expression, rather than open and direct expression of personal feelings, is likely to be valued as a means of ensuring in-group harmony." Third, with regard to judgment, causal reasoning, and attributions, "(a) social context, situational constraints, and social roles figure prominently in person perception and causal reasoning and (b) meaning is contextualized and memory is likely to contain richly embedded detail". Last, with regard to relationality, "(a) important group membershipsare ascribed and fixed, viewed as “facts of life” to which people must accommodate; (b) boundaries between in-groups and out-groups are stable, relatively impermeable, and important; and (c) in-group exchanges are based on equality or even generosity principles”. [31]

Self construals theory is has been build upon the individualism and collectivism by Markus and Kitayama [32]. Voronov and Singer cites from Markus and Kitayama that boundaries of the self correspond to those of one’s physical body for someone with a high independent self-construal. For preserving individuality personality tends to remain relatively consistent across different situations. Accourgin to authors for a person with a high interdependent self-construal, the boundaries of the self tend to be more fluid and more situationally determined. Authors cite that Markus and Kitayama suggested that people in collectivist societiestend to have higher interdependent and lower independent self-construals, whereas the opposite relationship is expected in individualistic societies.

Independent construal implies that construing oneself as an individual whose behavior is organized primarily by reference to one’s internal thoughts, feelings and actions rather than reference to others. In this construal person is more bounded, unique and integrated. In contrast, in interdependent construal person see oneself as part of an encompassing social relationship. Person’s behavior is determined and mainly organized by what the person perceives to be the thoughts, feelings, and actions of others in the relationship. [33]

There are several studies that explore cultural models of patient and its relation with doctor patient encounter. Kim and friends suggests that the greater the patient's construal-of-self as independent, the more positive her/his beliefs regarding patient participation, which, in turn, leads to a higher degree of motivations to communicate verbally with a physician. They also suggests that the greater the patient's construal-of-self as interdependent, the more negative her/his beliefs regarding patient participation, which, in turn, leads to a higher degree of communication avoidance and apprehension during medical interview [34]. Meeuwesen and friends argues that cultural dimensions like power distance, uncertainty avoidance, individualism and masculinity, together with countries’ wealth, are predictors of cross national differences in health care communication [35]. Schouten and Meeuwesen in their other study review the literature and identified the cultural differences as source of communication problems in patient doctor encounter. They have mentioned individualism and collectivism construct as one of the dimensions for explaning variations in communications between cultures. They have also identified influence of cultural individualism – collectivism on communication behavior as individuals' self construal in terms of independent versus interdependent [36].

CHAPTER 3

METHODOLOGY

This research conducted as a field study. Our domain is limited with breast cancer patients having their treatment in hospitals. Both care providers and consumers are included.

Research question of our study is based on patient empowerment and patients' perception of disease, and health care process. This relationship could be analyzed either with indirect information collection or direct observations. In this case direct observation is not possible due to the patient-physician privacy. Therefore we interview counter parts, physician and patients, separately.

In this research, we prefer in-depth interview method rather than survey. By this method we can examine all aspects patient empowerment and its' effects on physician – patient relationship. Limitation of in depth interview is time concern of physicians. Physicians had difficulty of allocating long time for interview. We expect that patients will volunteer to allocate their times. However they might get emotionally frustrated, since breast cancer patients are going through difficult treatment, and has deep concerns on their health status.

Sample

Our sample covers patients who have diagnosis of breast cancer and continuing their treatment; and physicians provide care to breast cancer patients as oncologist and surgeon. Sample size is not predetermined but three different health care provider categories included in our research. These categories are namely:

1. A tertiary health care provider: an university hospital
2. A secondary health care provider: a state hospital of Ministry of Health

For each category we are interviewed to 10 patients and 3 physicians. Our total sample size is 20 patients and 6 physicians.

State hospital and university hospital has been choose because of they have significant variations among their patient's socioeconomic conditions. State hospital serves as a referee hospital from rural areas. Therefore we had possibility to interview many patients out of Ankara. State hospital profile covers mainly lower class and lower middle class from provinces. On the other hand University Hospital mainly patients from middle class most of them highly educated.

CHAPTER 4

RESULTS

4.1 Patient and Physician Profiles

We have analyzed and categorized interviewed patients according to their education level, age, employment status, residence location, socioeconomic status, access to information technologies, and internet usage in breast cancer related issues. Hence we have conducted a semi structured interview, we do not want patients to state their status but we have asked related question during interviews.

Education level is one of the important factors in patient improvement. Level of education has been significantly varied between University Hospital and State Hospital. Among University hospital patients there were no patients graduated from primary school. Most of the patients, 6 of 10 patient graduated from high school, and almost half of the patients receive college or university education. This University Hospital patients sample is more above educated compared to Turkey’s women population.

On the other hand none of the State Hospital patients received higher education. Most of them primary school graduated. 4 of 10 patients have high school graduated.

Table 1: Education Level of Patients

	University Hospital	State Hospital
Primary School		S1, S2, S3, S4, S7, S8
High School	U2, U3, U7, U8, U9; U10	S5, S6, S9, S10
College	U1	
University	U4, U5, U6	

Breast cancer occurrence is increased with age. In our both setting, almost half of the patients were in their 50’s. We had only three patients over 60, and one of them was in age 73. Among young population observance frequency of is low. We had only two patients below 35. There was no significant difference according to age of population between University Hospital and State Hospital settings.

Table 2: Age of Patients

	University Hospital	State Hospital
30-39	U10(31), U6	S5(35), S7
40-49	U9(46), U7	S6(46), S8(43)
50-59	U1, U3, U4, U5, U8	S1, S4(52), S9(54), S10
60-69		S2(65), S3(69)
70+	U2(73)	

We have asked employment status of patients. More than half of them were house wife in both care setting. However remaining ones, working women has shown significance difference between care settings. In University Hospital all working women is white color highly educated ones, whereas in State Hospital most of them blue color and informal sector workers. In our analyses retired women has been considered with their former jobs.

Table 3: Employment of Patients

	University Hospital	State Hospital
House Wife	U2, U3, U7, U8, U9; U10	S2, S4, S5, S6, S9
Government Official (Academic Personnel)	U6	
Government Official (Technical Personnel)	U4, U5	
Nurse	U1	S10
Informal Sector		S1, S3
Farmer		S7, S8

Residential locations highly vary among care settings. In University Hospital almost all patients are resident in Ankara. Only one patient came from metropolitan hinterland of Ankara. On the other hand most of the State Hospital came from outside of Ankara. 6 of 10 patients came from other provinces; where as 2 of these 6 came from rural area.

Table 4: Residence of Patients

	University Hospital	State Hospital
Ankara	U1, U2, U3, U4,U5, U6 ,U7, U8, U9	S1, S3, S9, S10(Gölbaşı)
Other Provinces	U10(Kırıkkale)	S2 (Tokat), S4(Çorum), S5(Kütahya), S6(Bolu),
Rural Area		S7 (Şanlıurfa), S8(Yozgat)

Socioeconomic status is highly varied among care settings. In our interviews we do not directly ask household income. We based our analysis information gathered related to employment status of women and their husbands, their residential locations and education levels. This information has been provided a clue for socioeconomic status of women.

Result of this analysis, we have observed that University Hospital patients socioeconomic status is significantly higher than State Hospital. This has been an expected result since in University Hospital care setting patients has to make additional payment for their surgery. All of the State Hospital patients are belong to lower and lower middle class.

Table 5: Socio Economic Status of Patients

	University Hospital	State Hospital
Upper Middle Class (metropolitan)	U2, U3, U4, U5, U6, U7	
Lower Middle Class (metropolitan)	U9, U8, U1	S9, S10
Lower Middle Class (towns)	U10	S2, S5, S6
Lower Class (metropolitan)		S1, S3
Lower Class (towns)		S4
Lower Class (Rural)		S7, S8

We have questioned patient whether they have access in information and communication technologies. All patients from University Hospital care setting has computer in home. And 9 of 10 patients have access in internet from their home. On the contrary only 4 of the 10 State Hospital patients have access to internet from their home. One of the patients has computer but not internet access. 6 of 10 patients do not have any access to information and communication technologies. Among them three of them reported they have relatives out of household gather information for them from the internet.

Table 6: Access Level of Information Technologies

	University Hospital	State Hospital
Internet access in home	U1, U2, U3, U4, U5, U6, U7, U9	S5, S6, S10
Computer in home but not access to Internet	U8	S9
No access to ICT		S1, S2, S3, S4, S7, S8
Accessing Internet Information via Third Parties (outside the household)		S3: grandsons in England S8: brothers and sisters in urban area S9: son out of town

When we have analyzed internet usage typologies, most of the University hospital setting patients are actively using internet. Almost all of them use social networks, some of them use for playing games, or reading news papers. Two of them use internet in their jobs, only three of the University hospital patients reported that they do not use computers by themselves.

On the other side, none of the State Hospital patient use computers by herself.

Table 7: Main Internet Usage Typology

	University Hospital	State Hospital
Social Nets: Messenger, Facebook	U1, U3	
Computer Games	U1, U3	
Leisure: Newspapers and other web site access	U1, U4	
In her/his job	U5, U6	
For Research	U2:proxy, U5, U6	
Not used	U7, U8, U9	

When we analyze internet usage frequencies, 3 of 6 internet users reported that they use internet in everyday. Others use internet mainly on occasions. In both care settings proxy usage of internet, with the help of family members are reported.

Table 8: Internet Usage Frequency

Everyday	U3, U5, U6	
Frequently	U1	
Seldom	U4, U10	
Proxy Usage	U2: by daughter U4: by daughters U9: by daughter	S5: by husband S6: by son

When we analyze internet usage for breast cancer we observed that only 5 of the University hospital have seeking information related to their disease from internet. In State Hospital setting, we have observed that only two patients searching for information before the health care decisions with the help of their family members. In State Hospital three more patients mention that they have received internet information from their relatives out of household on some occasions, but this can not be considered as informing via internet.

Table 9: Internet Usage for Having Breast Cancer Information

	University Hospital	State Hospital
Everyday		
Everyday before the decision point	U5	
Frequently		
Frequently before the decision point	U2: by daughter U6	S5: by husband S6: by son
On occasions	U2: by daughter	S3: grandsons in England S8: brothers and sisters in urban area
Seldom	U3	S9: son out of town
Never	U1, U4, U7	S10

4.2 Encountering with Cancer: Self and Disease

Cancer is dreadful experience for women. Both in eastern and western cultures cancer are associated with death. Holland argues that for long centuries cancer has been feared because neither its cause not cure was known [39]. He states that during 1800s, cancer diagnosis was felt to be a death sentence and revealing the diagnosis to a patient was considered cruel and inhumane because the patient would lose all hope and could cope better not knowing. As a consequence, doctor and family keep secret from the patient and remain silence. Cancer perceived as stigma and shame, guilt and fear has been lead to social isolation of patient. In 19th century, with the development of anesthesia and antisepsis surgery became possible. Early diagnosis became important. So attempts to change the fatalistic attitudes towards cancer initiated. Holland states that disseminate knowledge concerning the symptoms, treatment and prevention of cancer policy are applied with such slogans as: ‘Fight cancer with knowledge’. Further improvements is achieved in the treatment of cancer with the first chemotherapy cures in 1950s and increasing optimism raised with growing concerns about information consent. Holland states further changes as follows:

> “The era of social upheaval in America (1960s-1970s) received strong contributions from the movements for the rights of women, consumers, and finally patients, who began to demand to know their diagnosis, prognosis, and treatment options. Breast cancer figured most prominently in the battles, in which women pressed for a two-stage biopsy and less aggressive surgery by primary treatment with lumpectomy and radiation.” [39]

Patient empowerment movements and facilities provided by information communication technologies changes the ignorance, fears and fatalism related to cancer. This historical rooted cancer stigma has been changing not only western society but also in Asian society. Chin and his friends [40] although half of the breast cancer women express their not knowing the genetic risk information because of their fears, younger and more educated women are more willing to embrace new knowledge.

Empowering is demanded by not only patients but also health care givers. Adamos argues that as a health care deliver:

> “our task as responsible holistic healthcare providers should involve a respectful approach; an approach that restores the person to a rightful place of personal empowerment. In this state, people can make decisions using their psychological, emotional and spiritual intelligence because they are empowered; therefore they can make conscious, informed, considered choices about any treatment they wish to have.”[41]

Knowing their diagnosis, having information on disease, and participating treatment decisions are the steps of empowering process. For this empowerment, patient’s relation with her diseases is an important factor. Patients might construct barriers of fear, guilt, or ignorance. And patient display different ways for coping cancer as a way of dealing all these psychological factors. And all these patients' reactions to illness effects her interpersonal relations and other's give response to her.

We are analyzed the patients attitude towards her disease before and just right after to diagnosis. Then we inspect their way of dealing with cancer, and lastly we explore their relations with family members. All these psychosocial conditions will be considered as a factor in patient empowerment process.

4.2.1 Fear of Cancer

Fear from the illness might appear much earlier than diagnosis with cancer. In some cases, patients were informed about their possibility of having cancer. In one of the our interviews, a high educated, upper middle class woman state that she had fibrocystic diagnosis before and had been informed by the doctor than fibrocystic might cause the cancer in future. This possibility cause fear in woman and lead woman to gather information from various sources. She has been access both Turkish and English internet sources, gather technical knowledge from informative web sites of hospitals and medical associations. She has learned anything related to breast cancer, including preventive controls. However, this harvest information neither helps to acceptance of the idea of cancer nor to lead the proactive behavior for early diagnosis. She expressed that for long years she has been lived together with "the fear of cancer". And she states that even though she has known everything on breast cancer and importance of early diagnosis, her fear hinders herself from having regular controls.

> *"I could not go to mammography, ultrasound. I could not go at all from the fear. Big apprehensions I lived. One I went I remove it out"[U5]*

In this case fear cancer appears before the cancer. She had been live together with this fear. She perceives cancer diagnosis and surgery as an end and begins to accept cancer. For another case, a high school graduated, upper middle class woman generates fear of cancer even though she is not in the risk group. Her cancer fear emerges by observing cancer patients:

> *"Twelve years ago I have lived a panic attack. Therefore I had to take medicine for years, I could not recover. The reason of that panic attract was*

> *fear of cancer. No one in our family has it (cancer). But friends and acquaintances had it. Last stages were horrible. God forbid to everyone, when you see these kinds of things you a lot..I am a kind of person who developed empathy. Therefore I become too afraid from many things in life. " [U7]*

These two women experienced cancer fear before the diagnosing with cancer, believe that their fear triggered the cancer. She relates the fear with the appearance of cancer:

> *"I become to belive that if you fear from it happens. Some of them says negative or positive charge so. Probably best way is to think positive." [U7]*

Similarly in other interview, highly educated information speaks out the doubts related with the fear and having cancer. As a university graduated intellectual white color worker, she seek for a scientific ground for relation between her anxieties and appearance of her disease. Her family also supports the idea of relating fear f disease and having of disease. She believes cancer is happen to her because she is too much afraid of it:

> *"May be fear make all these things happen. I think that may be if they do not say, it would not be happen. I wonder is it happenned because of groundless apprehensions. They say so, in scientific journals, you can manipulate your brain centers as you want. So my family says that you make it happen by thinking. Realy it happened because of my fear. I have afraid a lot" [U5]*

4.2.2 Reactions to Diagnosis

A person diagnosed with cancer is likely to be highly fearful and uncertain [42]. Most of the woman express the relation of death and cancer, and were distress by having diagnosed with this disease. Fear of death is a shocking experience for many women and it make complicated to accept disease and get proper medical help. We have asked our interviews the story of learning diagnosis and their feelings. In most cases patients experience fear when they heard the diagnosis because of the strong belief of cancer equals to death.

A 35 year old young, high school graduated woman express that how she has associate disease with the death:

> *"The day (I have learned I had cancer) I got shock. As a matter of fact that day, all day I have cried until the night. .. That was the one of day I do not want to remember. When I heard I could not figure out how I will deal. Cancer reminded me death. For a moment I feel like I am dying. But when they say is is limited with that place...they scan bones, livers, all interna organs. I feel a big relief. (cancer) Being limited with that place makes me relief too much." [U10]*

She believes that cancer equals to death and she has a relief when she got the idea that disease is limited with in the boundaries of breast.

Another high school gradate middle aged woman identifies cancer as a turning point between the death and life. And she expects that it is doctors' responsibility to handle this fear when diagnosis is proclaiming to patients.

> *"This is an important disease. Doctors should be carefully use words when they are uttering it. First expression, presentation is very important. Because when you hearing that decision (diagnosis of cancer) you are in a turning point between death and life. This turning point should be appropriately expressed to you." [U7]*

Many patient states that learning their diagnosis is a crucial point for them. Most of them were not prepared to the idea of cancer, and having trouble with accepting the diagnosis.

Another high school educated, lower middle class woman express how she has terrified when she had learn the diagnosis:

> *"They have done a kind of surgery. This much it they have taken, this much breast is remain. They took a part. I was awake, I feel everything, it was hurting. They send to pathology. When result is ready, I came to show it. I show it in polyclinic. I was feeling horrible when I am moving from doctor to doctor. When I think that moment, I can not believe. Some people get educated but not grown in to man. Shall this is declared to patient in that way? I make me upset. He said you are cancer, it should be removed immediately. At that moment I feel that I go into ground. I felt too terrible, my wits ended. "[U8]*

This woman was repressing the idea of cancer during the diagnostic examinations, was not familiar to medical processes, and did not clearly understand what types of test were undertaken. As a result she had been developed a fear from medicine.

> *"He say to me do not afraid. You had a trauma, we will fix it, we won't send you as long as you do not get well. I go to polyclinic for dressing the wound, before unroll I become to cry like a child. They ask me sister, does it huts? I say no because you had white apron" [U8]*

4.2.3 Coping with Cancer

How patient are cope with cancer is distinguishable research area for many years. Stress, anxiety, and fear are psychological factors that all cancer patients had to deal with. This coping mechanism is important not only because of they has psychosocial impact of prognosis of disease, but also it influences the empowerment of patient. According to Bean and friends the term of coping describes a continuum attempts by patients to maintain personal control over their lives. He states that there are two extreme sides in this continuum. At one extreme patient appear to abdicate personal control, they may feel completely helpless, deny the seriousness of the disease, delegate all decision making powers for health care to medical stuff and exhibit regressive models of behaviors in family. On the other extreme, patient may seek to increase control over their lives by learning specific illness related procedures for caring for themselves, setting self improvement goals to overcome any disabilities caused by their illness, and seeking relevant medical information that will enable them to evaluate and choose between courses of treatment [37]. Patients in these two extreme sides will exhibit different attitudes for information gathering and using. Coping mechanism can be one of the important determinants of patient empowerment. Dunkel-Schetter and his friends examined factors identified in the stress and coping literature and adopt most commonly used self report coping instrument, the Ways of Coping Inventory (WOC) for cancer patients [38]. In our research, we have used this adopted instrument to distinguish different coping mechanism of breast cancer patients. The scale consist of 'seek and use social support', 'cognitive escape-avoidance', 'distancing', 'focus on the positive', ‘behavioral escape- avoidance’, ‘dropped due to low loadings’. Following sub chapter present our result according to this scale.

4.2.3.1 Seek and Use Social Support

Seek and use social support pattern is characterized by talked to someone to find out more, about how feeling, who could do something; looked for sympathy and understanding, ask a friend or relative for advice, tired not to close off options, made a plan and action and follow it. In their study Dunkel observed that use of social support is strongly related to greater perceived stress from cancer and associated in bivariate tests with more functional limitations, and more frequent worry about cancer and higher levels of education [38]. In our study, although some of patients express their attitude to ask a friend or a relative for advice, none of them has cope with cancer by seeking and using social support. Most of the patients are tent to share experiences with other patients in waiting rooms, but for none of them it was main cooping way. Only a lower middle class nurse delegates herself a mission to form a social support group in waiting rooms and support psychologically to other patients:

> *You are binding a patient physiologically, then physiologically, radiological, chemotrapitically. You have tried to bind with many aspects. When I came here, if I see sullen face nurse or any one else, except doctor, I have frightened.” [U1]*

4.2.3.2 Cognitive Escape-Avoidance

Most of the traditional religious women from rural areas expressed that they will come through this disease with the help of God. They imply that this disease is a sufferance and can be cured with only with the help of God. They use the phrases such as:

> *“We neet to be patient”, “this world is for testing” [S2]*

Another patient, high educated white color worker express her rejection of cancer idea as follows:

> *"I have rejected it from consciousness. What if I said something out of consciousness as nothing but I do not know anything yet. But there is nothing. "[U4]*
>
> *"I try not to think" "The other day I looked at things. I am listening to television programs, new test are found. I am trying not to think. I forget everything when I am sleep." [U3]*

4.2.3.3 Distancing

Most of the women were rejecting the idea of having cancer in the beginning. During diagnostics testes and regular controls, most of the patients believe that it would not end up with cancer diagnosis. In some cases even after the diagnosis, women feel that cancer and they can not be matched.

Many women use the phrases as :

> *"I did not want to accept that" or "I was not for me" [S9] , [U3], [S6]*

A non educated middle age house wife expressed that after learning that she had cysts, she had doubt of cancer. But reject the idea of having it.

> *"I was hearing from the acquaintances, television, but I thought it is not for me" [S6]*

She does not want to talk much on because negativly affected. She does not mention cancer term.

A very high risk group intellectual woman has express similar rejection situation:

> *"Something was growing up there, but nothing ever happen to myself then it would not, but I began to notice a significanly"[U6]*

Since her mother die from cancer, she has regular controls. She has informed on cancer, regularly reads on scientific documentations, and having regular controls. However she misses her last control. Then she realizes a growing cyst. But she suppresses the possibility of cancer.

4.2.3.4 Focus on Positive

Some of women express their need for spiritual beliefs. And also some of them recognize the cancer as a new way of life, which they can prune evils of former life.

Another high educated middle class woman says that her life has been changed by the diagnosis of cancer:

> *"I think I am a good patient, since, at first smoking, my greatest weakness, after that turning point I start a brand new life from here. Nothing came here from that old life, smoking cafe. And for example I had been never careful in my diet. Just like a new order I train myself" [U4]*

She meditates and applies quantum thinking and some healing meditations. She believe that it is a purification process for her:

> *"I was asthma patient, thyroid nodules, liver problems, stomach hernia, herniated disc.. And now I have not taken even aspirins. And I think that it is a cleaning. This is a blowing event as a result of toxins mass for years, using life in a wrong way, and it is cleaning. It is cleaned; I think it in that way."[U4]*

A nurse having breast cancer emphasize importance of being spiritually strong and express than this disease was a new way of life for her.

> *"You are reviewing your life and open a new door ... a mirror. A wall from love is built around me... it is important to receive prays.... I never said I'm sick; I've looked at life with a smile. Having strong in religious way is requires" [U1]*

4.2.3.5 Behavioral Escape-Avoidance

This type of coping factor is associated with time since diagnosis. When more time elapse from diagnosis, patients are more frequently using this mechanism. In out setting most of the patients were receiving their post adjuvant therapies. One of the patients, a nurse who has diagnosis long year ago states that:

> *"it is good for them to learn in a simple manner… yes they will spend some time in internet, they will know their disease, what is this what is that, this is a very good thing,. But they should also dedicate to themselves to other aspects, making sport, listening music. I am not against to internet, they should learn, because it is the requirement of our age."[U1]*

Another patient who is receiving post adjuvant treatments however live long years with the idea of cancer report that:

> *"..he said that the way this disease is, people will get sick in certain time, you should not worry, you will enjoy your life, you won't mind. He said the truth. He did not disturb by exaggerating (or) not paying attention or too much paying attention. "[U5]*

4.2.3.6 Dropped due to low loadings

Most of the rural or lower class woman does not distinguish cancer disease from the treatment process. Most of them have not been informed from diagnosis. They have been learned together with surgery treatment decisions. Therefore they perceive cancer and all treatment process as integrated concepts.

Old women from a small town quote her experience as follows. She has realized cysts when she have hospitalized from another disease. However she does not tell doctors:

> *"Doctor asked why you have not say to us, I got shy I did not say."[S2]*

After couple of tested they start to chemotherapy. They do not explicitly state that she got cancer. So she is informed only on treatment processes:

> *"they said that we can not give drugs. They said that it has become smaller, it needs to be taken with surgery; doctors said it got smaller take it away" [S2]*

Most of the uneducated patients do not speak on cancer. They mostly utter their physical conditions, disturbance, and pain.

An uneducated lower class woman from urban states her experience as follows:

> *"umm a cyst appeared in my arm, I went to get test. They said cyst, it will recover by it self. As result it is recovered. ..for a time ago a said cyst in my arm not gone for a long time. More a fuzzless begins to form. About 10 days I begin to swell up. I did not know this disease. I swell up from kidneys. I swell a lot. Water flows from my noise. I said to my self I go and look why it happens like that. I found a free time then. I than said to my test, then in my free time from my breast. .. I came to examination to doctor from my breast. They said we can not tell in one day. I keep coming for results."[S1]*

In her cognition, rather than diagnosis, tests, disease, treatment process, there are physical signs and orders of doctors.

4.2.4 Interdependency of Self

Almost all women we have interviewed tent to construct and interpret cancer reality in a collective manner. This collectivist psychology is observed both in taking decisions on their body, treatment decisions and on their anxiety to not being able to fulfill their social role in family.

Total mastectomy surgery results with removal of breast, and inevitably breaks down the unity of body. This is an important decision for women. Almost all women take this decision collectively mainly with their husband and family. In some cases decision taking extends to large family. A lower middle class young women states that she take her decision not only with her husband but also with her other relatives:

> *"Yes my sister, broter in law all together, we discussed what doctors said."[U10]*

Breast also represents sexuality. Therefore women who are highly interdependent self construal are tent to delegate decision to their husbands. Upper middle class women states that she takes decision by having permission of her husband:

> *"I take my decision by discussing my husband and children. I asked to my husband is it important for you. He said that it is not important for me, what ever is it required for your health do that" [U7]*

In lower class women the authority for decision taking shifts to husbands. Husband takes the decision of total mastectomy without asking the thought and feeling of woman:

> *"(doctors) asked, they all asked, should I remove or not. I said remove, I do not want it to give harm"[S4]*

In our interviews only one highly educated, intellectual upper middle class woman presents high independent self construal and act individually in her medical decisions. She defines her boundaries and medical professional boundaries clearly and decides by using rational thinking. She has unity of self and use individual values in judgment and decision making.

> *"I search as far as I can. I am not doctor. From the beginning a weird thought has been clarief as keeping my body as a whole, not separating parts as far as possible. I try to protect as it is possible"[U6]*

In collectivist cultures persons related their well beings and emotional expressions with life satisfaction deriving from successfully carrying out social roles and responsibilities. In our study some of the women expressed their anxiety on distortion of their well being.

A high school graduated middle class house wife hides her diagnosis from her children until surgery. She is very disappointed from not playing her cheerful mother role in family.

> *"I have knowingly sacrifised my self. Thought I had to go chechk up evey month. I knew. Spending time for my self seems unjustifiable. I rush all over; I have done everthing in home. My children could not get believe. Sudenly a mother doing everything get sick. It was the most sorrowful thing (learning of childeren) otherwise if I has surgery.."[U9]*

This woman prefer to hide her surgery from their childerens:

> *"I have only explain to my doughter, since she know my doctor personally, I said my doughter he said this and this, we take a biopsy, inspect it, we do not live a fearfull think in future. But I will stay over night in there. She said ok mom, go and done it. I said you stay in your aunt. She stayed in my sister. My sister keeps busy her. I had surgery and next night I have come home. She said that let me look what have taken where. Drains were pluged in. Then she learned at that moment. [U9]*

Uneducated lower class women felt guilty to spend their families' resources for their health problems. 52 year old house wife from Çorum has realized problem by pain. She does not tell any one and put ice on it to relief. She had a car accident before and she thinks than her illness is a burden for her family. Although her husband is retired, she do not want to take his time to go doctor with her:

> *"I could not go because of our jobs, disease overwhelmed our program."*

Then when wounds were appears. She still keeps silent and do not tell any one, neither her husband nor her son. She expresses that no one like to see her as ill:

> *"I did not want mans know it, because of I am women. They have programs. No body wants to see patient" [S4]*

Another woman from Urfa, utters that she has no expectations related with her health care, she only wants to look after her children as before

> *"I did not have any expectation. I just want to stand up and go. I look after my children" [S7]*

In high interdependent self construal boundaries of self is more fluid. A young middle class women living in Kütahya trusts her husband and feels support of him:

> *"my greatest supporter, my strength is my husband. If I survive today I own him" [S5]*

4.3 Involving the Health Care Process: Self and Care System

4.3.1 Perception of Good Doctor

Perception of doctor reflects patient's attitude and expectations from health care delivery system. Doctor as an authority figure, handles fears, anxieties, expectations of patients, and lead the medical decision treatment decisions. In our interviews we have asked patients to define what is good doc? They emphasize competency in professional knowledge, reliability, providing support, providing options, providing information, and handling anxieties as main qualifications of doctors.

4.3.1.1 Competency in Professional Knowledge

Some of the patients state that most important expectations from their doctor are professional expertise. They omit other psycho social factors, and construct goodness criteria around professional knowledge and expertise. A 73 old woman state that:

> *"a good doctor shall make good treatment. Some people speak and speak, but not have good medical skill. In my opinion that not gives much benefit. Doctors own thing should be good"[U2]*

Similarly another 69 year old woman expresses importance of professional knowledge:

> *"When he examine to me, even though he does not known everything, if he knows something on your disease. Anyhow you understand that" [S3]*

These patients were the oldest patients in our interview sample. Because of their ages, they might not directly relate breast cancer with death. Therefore rather than psychological factor, they have focus on achieving best care possible.

4.3.1.2 Involving Patients to Decision Processes

Participating decision processes is important for empowered patients. However in cancer patients willingness to involving in decision making is not common. In our interviews only one patient was willing to declare her preferences to her doctor and involve decision process. In her good doctor definition providing options appear as an important concept:

> *"A good doctor who would be able to tell options directly on my face, he tells what happens, give me correct information, treat me good, the one I believe he is competent in his domain." [U6]*

4.3.1.3 Information Provider

Breast cancer patients are generally unwilling to search information from various sources. They are tent to depend on information provided by care givers. In our interviews most of the State Hospital patients expressed their expectations of information from their providers. These can be precedent by several reasons. First of all State Hospital patients are socioeconomically from lower and lower middle class, most of them came from rural areas and do not has access to information sources such as internet, informative documentations, so on. Even though they can access they do not have enough infrastructure to interpret obtained information. Secondly, they are more drawing more clear lines between themselves and professional knowledge. Most of the patients do not interest diagnostic procedures and details of their diagnosis, or treatment alternatives, rather they consider reflection of disease on their bodies. Lastly, in contrast to University hospital State Hospital does not have any informative or educated program towards patients. Patients can not receive any printed material or orientation session from health personel.

> *"I want him to enlighten me, I want him to communicate with me, inform me. Some doctors do not enlighten, give no information. They look to your thing. And then I want to learn exactly what kind of disease" [S9]*
>
> *"I want him to explain everything to me, inform me"[S6]*
>
> *"someone when you want you can walk in to, some one you can see. I can not see doctor. They say he is in surgery, will be back in 15:00. Last time*

> *there are 4 doctors in oncology, we can not get any information if there is progress or not. When I ask they say later" [S7]*
>
> *"my doctor was so goog. He was so interested. I am expecting the doctor to provide information" [S8]*

A young lower middle class patient from University hospital defines expectations from her doctor as follows:

> *"First to be cheerful and friendly, give detailed and explanatory answers to the questions we get asked, nicely explain to your questions and things you had to do is a must." [U10]*

She defines dimensions of information as clearly answering patient questions, informing patients on supporting behaviors, giving detail and informative explanations.

4.3.1.4 Trustable Godlike Figure

For patients trusting her doctor is vital for receiving a good treatment. Most doctors also believe that trust of patient facilities the doctor patient communication, and even with absence of trust successful treatment process can not be accomplished.

A university graduated upper class woman states that trusting the doctor is prior for her. In this case trust means acknowledging doctors professional expertise, justifying impolite behaviors, further more giving a godlike role to her doctor:

> *"Trust is first. That should be honest to each other. For example, my oncologist is very grumpy man, but the work of the patriarch. That has been shed on this patient was broken. For example, he says I have patients now shut off phone. First I have got upset, why he treat me like that. But when he examined me, I am under examination, other's call him and I have got what he meant. He is just exeminin patient, got fully concentrate, from the other side people calls and ask a lot of unnecessary questions. They are taken doctors time. He did the same thing to him, his own son. Ha I said this is the he is. I am 56 years old, you get angry resentment. But do not scold me. Man, it's something Business is doing very well indeed."[U4]*

A low educated, lower middle class woman again emphasizes trust factor. For her trust means relief anteceded by gestures, words, kindness of doctor:

> *"I do not know, at least the way he talks should give you a trust. Speaking style, whether for examination, whether he approaches people, I do not know, whether I need to find his confidence. I was at my waist has surgery here.*

> *Doctors had operated on. I've been out here two surgeries in the third. If the doctor is really good, both your psychology and in pain is going well. When I came to the doctor he welcome me at door. He gave me the confidence. We have gone to the doctor from being hurt I do not remember his face was ben. We went another doctor there he examined me, he spoke to me, he care to me, he explain what cen happen. When I go out, It comes out here so if I let go of a bird cage or something like that, I felt. I said to my wife that the doctor is very good. "[U8]*

Another middle class woman express her gratefulness from trusting her doctor:

> *"It is very nice to trust your doctor" [U3]*

4.3.1.5 Supporter: Handling Psychosocial Barriers

Psychosocial support is an important aspect in the cancer treatment. In patient doctor relationship, doctor thought that they should try to understand fears of patients [43]. Akmansu states that, doctors do not expect to tell whole truth to patient but it is important to not tell lies in purpose. In some cases even though benefit of treatment is suspicious, it is important to not to dishearten. If progress achieves it should be told to patients, however if not it should be very careful in behaviors and speeches not to loss hope of patient.

A well educated upper middle class woman expresses the importance of behavior of doctor. She defines good doctor as who puts right emphasize to prognosis of disease while telling truth:

> *"Right of speech, first of all to build trust. Not too exaggerated. Is normal, disease accept for me to build trust. He said that the way this disease is, people will get sick in certain time, you should not worry, you will enjoy your life, you won't mind. He said the truth. He did not disturb by exaggerating (or) not paying attention or too much paying attention. Uttering disease and saying that it isi normal build trust"[U5]*

Another middle class woman less educated than former, express similar opinion:

> *"This is an important disease. Doctors should be carefully use words when they are uttering it. First expression, presentation is very important. Because when you hearing that decision (diagnosis of cancer) you are in a turning point between death and life. This turning point should be appropriately expressed to you." [U7]*

A lower middle class woman experiencing high anxiety states her expectations from doctor as follows:

> *"A good doctor should not distract, should not be talking in circles, to say directly. So leave me no contradiction. Because I'm already having stress. He should tell me direcly so that my pain ends right away" [U9]*

Possibly she has experiencing distress caused by uncertainty and perceives that knowing naked truth will help to remove psychological pain.

Most of the patients express importance of friendliness of doctor. When they feel they are welcome, they can ask questions more easily and obey treatment protocols despite of physical pains.

> *"You expect that when you get into inside say how are you, be cheerful, give good answer to your questions, do you expect. Sometimes a doctor will answer questions you hum and haw" [S10]*
>
> *"Most of it being frienly to patients. Of patients waiting for this. Thanks to him my docos is very good very friendly doctor. If they are extra rude I can not bear this challenges, this pins. The reaseon for me they are gentle"[S1]*

Doctor's closeness can be important for cancer patient to support them in treatment process. They can feel as a part of team and it gives them strength in the fight against the cancer:

> *"they have act very friendly, wonderful. In the, in Bursa, in Kütahya. Esspecially my doctor in Kütahya. He is a vrother, people who are giving power to struggle" [S5]*

4.3.2 Choosing the Provider

Patient mainly has two important decision points in their health care process. First one is choosing their providers, second one is deciding on her treatment. Treatment decision is either taken by doctor or by patients with the strong suggestions of doctors. Only for limited cases, patients are capable of choosing their treatment among the offered ones. Therefore choosing doctor is only practically meaningful decision taken by patients.

In Turkey's health care system if a patient does not spend money from out of packet, means that her expenditures are limited with health coverage, she can choose her provider but in practical it is not possible to choose her doctor. On the other hand, if patients are willing to make out of pocket payments, she can choose her doctor. In our interview setting all State Hospital patients are covered by general social security and can not practically choose their doctors. Most of the State Hospital patients are referred by provincial public hospitals. On the other hand, all of the University hospital patients pay fee for their doctors and surgery; therefore they can choose their surgeons and oncologist.

Therefore we have analyzed how University hospital patients choose their doctors. All of the patients express that they choose their doctors with a personal reference of someone known. Some patients take second opinions before choosing their doctors, other obtain information form internet to support their decision. But all of them look for a personal reference before they have decided.

4.3.2.1 With Reference of Someone Known

Most of the middle class women choose their providers by recommendation of someone they have personal relation. They are trusted to recommended doctor and they continue their treatment with them.

After experiencing biopsy intervention in a special hospital, a middle class woman accesses her doctor by recommendation of her neighbor.

> *"My neighbors here in the apartment. Well said that... I want you to go this docotr. Because it is good for us, for me, if we can pass as much as patients to that side. That is a good thing to helping. Then I came to that doctor. God bless thousand times. He is the best doctor"[U3]*

Neighbors and relatives are also main source of references for choosing doctors:

> *"My doctor refers me to general surgeon. A biopsy required. He said keep your mind calm. It does not seem a bad thing. He refers to there. General surgery gives an appointment for another day. Later I called my neighbor. She had two patients with breast cancer, I like to learn doctors from her. Than they have examined two mammography. And said that there is something is seen here. Then I found my doctor. My neighbors brought their patients. They praised as the masters of this work."[U7]*

> *"My sister-in-law called me on Tuesday. The appointment was in February 5th. But she said you go into oncology, I immediately went to on Wednesday. Mammogram was taken on Wednesday. It was examied, and ultrasound was taken immediately. I gathered all the results on Friday showed the results to the doctor. Doctor said Immediately go to radiology department, I went down to the. In there they said come Monday we will evacuate there. I said okay. I call my sister-in-law said. She asked what happened. I said this and that. She said do not intervent, wait and let doctor in Education and Reseach Hospital will see. " [U8]*

Other upper middle class woman chooses her doctor with the reference of her friend:

> *"I did not investigate any other place. In a strange way I had an abnormal degree of trust both my oncologist and surgeon. I did not need to do research in another" [U4]*

4.3.2.2 Having Second Opinions and Internet

In our analysis having second opinion is very is very common behavior among University hospital patients. A lower middle class young woman living in Kırıkkale, first decide to receive health care in Ankara, then gets second opinions from several doctors about the possible treatment options. Then they discussed with her family and choose her doctor:

> *"We come from Kırıkkale. My sister lives here. When they say it should be romove, I do not want to do it in there, I want to come here. When we came here, we got opiniton from a few proffessor. All of them agreed to remove it..... looked at the results, as we go from three professors, (my doctor) told the same thing, it should be removed. May be partially, but then also said the risk of recurrence. We thought,... at first, my husband, mother, even my sister and brother in law discuss what doctors told."[U10]*

Another upper middle class old woman is encouraged to take second opinion, even though it is expensive, by her well educated daughter:

> *Her doughter: "For example, other hospital said immediate surgery. I said do not decide with one doctor. These is a doctor, at first since she is an expensive doctor she do not want. I said no go her as well. Take her idea on this issue. When she say surgery we begin to look for a surgeon. So we do not take a decision in a sudden."[U2]*

Only one of the active information seekers use internet information for deciding their provider together with references personally known

> *"I researched the internet about it again, I found the my doctor. Through the hospital, doctors knew him (my doctor) are proposed, when I have read his biography from the Internet, I see he is a specialist on this subject. More easily naturally. We got an appointment from him. As soon as he examined he said the following day surgery."[U5]*

On the contrary, one of the active information seekers intellectual refuses to use internet for her doctor choosing decision:

> *"Be trusted one and a known one. On the Internet, you do not know anything when you enter. What would you choose? Who would you choose? The information is very wrong there. Through one of the more familiar. Is he good, is he reliable, is he how. Personal experience is more reliable." [U6]*

> *"In this case, I choose visuality rather than the internet. Beacuse lived experiences are more important for me. A man you do not know might be proffessor or what. Might be popular, might be scientist . First of all my respect forever. Def But I perefer to get contact with people who have tries them"[U4]*

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4.3.3 Husband's Role in Health Care

Many participants make own decision through health care process. Especially well educated upper middle class women, take their own decision even though they have received advises from their children. Most of the high school graduated middle class women living in urban, get help of their husbands in their interaction of health delivers because of their fears. And some of the lower class women living in rural do not involve in health care processes as actors. They delegated their husbands to make treatment decision and physician encounters for them.

4.3.3.1 Delegation of Husband

Some of the high school graduated middle class women receive help of their husbands in their interaction of health deliverers. Since they distress from confronting their health status, they have assign their husbands as buffers.

A middle class woman, divorced, trusted her ex husband for treatment. She got anxiety for hearing test results, so she delegated her husband:

> *He (ex-husband) go an get it. I told doctor on the phone you say now. I do not want to hear it. He said there is nothing. I trust my sugeon so brought to my sugeon today. Let's see what he will say" [U3]*

Another lower middle class woman's husband takes test results and shows doctors. Woman informs on her health status via her husband:

> *"What is the best thing, doctors say to me right things. By the time others look at me by pity I wonder if there is something wrong? Sometimes my husband shows the results to doctor. Then he did this I ask him is there any thing wrong, please just tell me so. I told my doughter is my doctor said something to your father." [U8]*

High school graduated lower middle class woman takes the responsibility of her health care decision. Ideally she thinks that her husband should take the responsibility however sine her husband gets shock, she takes the control:

> *I went only with my husband. I have no one else with me. Because I did not tell anyone. My husband was a little shocked. When it happens, I had to talk with my doctor about these things. I said that I'm ready. .. He could not believe (her husband) a little bit. He began to say god willing so on. I said that I'm ready to talk to me. Because I did not have anyone else" [U9]*

4.3.3.2 Authority of Husband

Some of the lower class women living in rural do not involve in health care processes as actors. They delegated their husbands to make treatment decision and physician encounters for them. In some cases, husband delay women's access to health care.

A lower class house wife from Çorum, has no power to take her medical decisions. During chemotherapy treatment she never saw her doctor, her husband act as mediator. For surgery decision doctor asked whether to apply total mastectomy or preserve some of breast, again her husband make the decision:

> *"Of course he asked, they all asked, should I remove or not. I said remove, I do not want it to give harm"[S4]*

Her husband asks questions to doctors on behalf of her wife:

> *"I asked what happens after this operation .... I asked the cause of symptoms such as swelling"[S4]*

Husband takes all the right and authority on her wife's health. Woman has no direct contact with health care providers and become subject of her husband's decisions.

In another case, 46 year old lower middle class woman from Bolu, treatment process is managed by her husband. She is cardiology patient had a complication during chemotherapy treatment and this complication risks her life. Her husband act as a mediator between cardiology doctor and oncologist, take the responsibility and manage to process in order to minimize risks:

> *Her husband : "We have doctors who do heart surgery. I am on the ongoing dialogue with him. Daily phone calls, I am informed by telephone. I say this happened, they say in this way it will happen so on. If he says stop chemo I will stop if he says keep going I will keep going."[S6]*

43 year old, uneducated woman lives in village of Yozgat, her access to health care is delayed by her husband for two months. Although she has complains, she has been delay first encounter for a long time. Then she went to an acquaintance doctor by herself:

> *"I take ultrasound and sen me to here hospital.. They said you have to go urgently. That doctor was our acquaintance; he did not give much information" [S8]*

When she came to Ankara, she does not know possibility of cancer. They ask for biopsy, but she does not know why. During the biopsy has been taken, doctor mention the possibility of cancer to her husband and she hear that. Biopsy result has been taken by her brother. Her brother does not inform her, he inform her husband:

> *"Biopsy result is taken by my brother living in here. They said him malign. My brother did not inform me clearly."*

Her husband reject to send her for treatment. She had pains:

> *"I had too much pain, it was 6 centimes.. I wat to come, I want to get rid of pains. I had got surgery then I do not have much pain"*

With the strong insist of her brother, her husband had left no choice, consent to biring her to Ankara for surgery.

> *"My brother is called. He keeps calling continuously. But mine is delayed. I came here 2 months after biops. My husband get afraid, did not bring to me. He is afraid that they will remove. I consternate. (my husband) even do not want to bring me here, he did when my brother is pushed"*

In lower education and lower socioeconomic classes, especially in rural areas, husband's authority on wife's health gets stronger. This might hinder accessing health care for women. However in middle class, more urban areas, husbands play more supportive role for managing women's fears on cancer.

4.3.4 Doctor Patient Communication

4.3.4.1 Feeling Connected and Resignation

In our study, we have not directly observed doctor patient communication. Instead we have interviewed women by basically asking whether they can ask questions, how their doctors response them, and so on.

Most of the lower middle class and middle class women in University hospital state that they feel free to ask questions to their doctors. However when we have examined content of the questions they are mainly related with life style such as "can I use saccharine?" or "can I play computer games?". A middle class woman expresses that she can easily communicate with her doctor by asking question related with her lifestyle:

> *"I can ask everything to my doctor"[U3]*

However same woman does not now her grade of cancer information and she can not ask directly to her doctor. She expresses that she attempt to ask and then decided not to do:

> *"Yes, I said to my doctor…Professor..(stop and think) I can not ask him much… " [U3]*

Another lower middle class woman from University Hospital express that she feel free to call her doctor when an unexpected situation happens:

> *"(can you ask question to your doctor) Sure. For example, when the first stream flowed like ink. I do not know ... ... that it had no seams. I'm soo afraid my hand and feets got so weird. I opened the phone to my doctor; it above my head went down as the ink is flowing I said. He said do not be afraid if you had anything in the house change it. Come to my office tomorrow, he said. I said doctor I can not look, better I go to the clinic. He said ok but do not let them touch. Only they change dressing than just closed. I came the next day I*

> *said sorry I called, he said it does not matter, even if midnight if you have problem call me" [U8]*

Same woman do not ask questions related to her diagnosis and treatment procedures. Although doctor patient communication is established in trust and continuity bases, she is not willing to involve medical domain. She express that she does not have questions by herself:

> *"I did not any question in my mind by my self. I had questions when I show results. I ask to my doctor does them for controlling? I was not expecting otherwise. He said result is clean; there is nothing in the remaining parts of breast, in bone. He said to nurse give stanch to her; if it is needed she can change in home. I call in night, I say sorry to disturb you. He says welcome, you can call. That is enough for me. Last day I have brought my daughter. She said you are right mom; he is very polite, I understand why you have liked him. I become very well after surgery". [U8]*

For University Hospital patients accessing to doctor is most important value. They feel in complete reliance and they experience resignation to their doctors.

> *"I can call my doctor each moment. He can answer any time. I he do not call back, he call later…. I do what ever he says "[U5]*

4.3.4.2 Restricting Herself

Some of the women apply self control mechanisms in communication with their doctors. They are constructing barriers; they have distinguished appropriate and non appropriate questions:

> *"I ask of course, when it appropriated and needed I ask my question "[S6]*

As a result of unequal power relations women might feel that they are not valuable to take time of their doctor:

> *"I can ask. But .. in his standing asking questions…I had concerns. I thought he is very busy person I should not distract with junk questions. Doctor works for an important disease, and if I ask all questions in my mind I might distract him unnecessarily. If I act like that this person will be tired of at the end. May be I would not be asking question I had to ask in future"[U7]*

These patients communicate with nurses which construct more equal power relations:

> *"I have asked to nurses. I got support from them. I did not live a very important situation. But I ask what is in my mind. "[U7]*

4.3.4.3 Appreciation to Doctor

Another result of unequal power relation in patient doctor communication is thankfulness of patient just being allowed to speak out. Most of the lower class patients on State Hospital are appreciated to their doctors when they have involved in communication:

> *"Ohh they care you very well, they listen you very goog much much, when you fo they righ away say let me look..."[S2]*

Some of lower class women are afraid to be exposed to misbehavior. They are appreciated when they are not:

> *"doctors do not get angy to me at all.. I ask, sometimes I say, son can I ask one thing. Tthey say ofcourse aunt, ask. I ask, he says aunt you got much, you know everthing.".[S3]*

4.3.4.4 Motivated by Doctor

In some situations doctor foster patients to actively participate to communication:

> *"If appropriate I ask. For example in first two threaphy my doctor said come on ask me something. I did not yet understand what happens. You say do this, I say ok. Let me identify it with myself. I will write down, don't wory, I said. Really in third threaphy I ask questions one in other. A question come to my mind, I say I should ask to doctor and take notes in home"[U4]*

4.3.4.5 Absence of communication

In some situations patient in State Hospital express that they have not any communication with their doctors:

> "I can not communicate with my doctor yet. "[S4]

4.3.5 Involving in Treatment Decisions

Most of women prefer not to become active in their treatment decision. Since we have interviewed with patients had or has been preapering for surgery, it is a difficult decision for them. We have analysed only four of the patients had active role in their treatment decisions. Amoung them, only one of the woman involved the treatment decision. An intellectual woman has been determined her preferences on her body and accomplish it through selecting right treatment option:

> *"They already asked me lumpectomy or mastectomy. Doctor gave me the option. I chose the lumpectomy between the two. They ask things that patient participation required for decision-making process. When they asked me, I say my own thoughts anyway. I expressed them as much as possible. I am not a thing (expert) in this area. So, I can not say know this, this would happen. But I can use options as much as possible if they are given to me. "[U6]*

Other active patients are only searched and questioned on different treatment alternatives, but do not involve in decision. Ratter they have role of inquiring doctors decision.

> *"If three doctors say same thing, I said just done it and finish"[U2]*
>
> *"He help me to accept it easly. He said your breast would not be removed. But after MRs and all other things. He came before the surgery and said that my breast could be taken totally. But id I desire he said he can leave. Because his opinion is valuable for me I said take it. That make me little bit upset" [U5]*
>
> *"Doctor said my age is too young it is better to take all of it, it is risk of reoccurrence in future, and in other circumstances even if inside is taken in future there would be a second surgery. I said especially that I want to get into surgery once and get rid of it" [U10]*

Most of patients prefer to be passive in treatment decisions. Some of them only notified by their doctors, other prefer not to take the responsibility of the decision and drop it to their doctors or husbands.

Most of the lower class patients from State Hospital is only notified by theier doctors:

> *"They told me I will go though chemotherapy, that thing will shrink, than I will get into surgery. Therefore I came here. They said it is good for you and for us in surgery. We shrink that disease and remove it all they said. It will not happen in future. I said ok and come. I am here today" [S1]*
>
> *"They said aunt, we can not give drugs. Aunt, it has shrink, we have to take you in surgery, doctors said it is shrink lets take it"[S2]*
>
> *"Let me tell, biopsy result have been told to my husband, my husband did not told me, I learned in here. It was difficult for me, doctor told. I have breakdown, I cry. I ask for permission. I have persuaded by doctor. Doctor is persuaded to me and we did not go anywhere else. Diagnosis has taken in this hospital. We did surgery in here."[S6]*
>
> *"(doctor) if I taken deep inside what you say.. it does not matter for me, what ever you say that it, what ever you want take that way. But I said I can not take another surgery in a few years. "[S8]*
>
> *"I left to doctors, so we trust them and leave ourselves. We said what ever needed do that" [S9]*

Most of the middle class women prefer to left decision to their doctors:

> *"I am very pleased from my doctor, god be pleased with him, did nothing to me, he take me in surgery between, It is already late he said. It was not my surgery day but I had to take you in emergency"[S5]*
>
> *"I do not listen to anybody on these subjects. Because patient doctor dialog is very important. If you trust your doctor, %50 percent of treatment responses positively. I am not medical stuff, of have specialization on this subject. That is best way for me, I go to my doctor and talk. We positily interact. Then I leave myself to my doctor "[U4]*
>
> *"While we are wondering whether it is true or not, should we go to another doctor or removed it, my youngest daughter get afraid from all of these . Said come on mom, our doctor is good, we know that, we trust him, removed it do not wait mom. Hence she insist we went doctor next day without investigate" [U7]*
>
> *"My doctor said: 'results are bad. We do not get you stress by taking biopsy and waiting 20 days. We take it all. Anyway during surgery biopsy result will be taken. In the meantime result came immidiatly, then I can decide according to result.' Result has been bad anyway. He take away totally, but with my approval. I said what ever happens, my breast is not important. As long as I have got well"[U9]*

In some cases husbands become the decision maker:

> *"(doctors) asked, they all asked, should I remove or not. I said remove, I do not want it to give harm"[S4]*

An upper middle class high school graduated religious and liberal woman asks her husband for total mastectomy decision:

> *"I take my decision by discussing my husband and children. I asked to my husband is it important for you. He said that it is not important for me, what ever is it required for your health do that" [U7]*

4.3.6 Power Relations

In our study power relations in medical encounter is analyzed according to prototypes of paternalistic, mutual decision making, consumerism and supplier. In patient doctor relationship if patient has low power and doctor has high power it leads paternalism, if both side have high power it leads mutuality, if doctor has low power and patient has high power it leads consumerism, if both parties has low power it leads default supplier relation. In our study there were also cases with absence of any relation.

Patient: U1 / Prototype: Paternalistic

Statement:

> *" My doctor is very important for me. Because when I saw his face I feel trust. Yes he is right beside me. When I am going to surgery I remember a hand, said do not worry I am with you, I will take your breast"[U1]*

Patient: U2 / Prototype: Mutual Decision Making

Statement:

> *Her daughter: "It is like this. When a diagnosis is taken I have intervene. I look what can be happening, who suggests what, like that. Since I have worked in medical school I am visiting radiologist, oncologist and ask them "*

Patient: U3 / Prototype: Paternalistic

Statement:

> *"After first biopsy I have taken up a heavy thing. My surgery place was large, around 12 stitches. I had taken up a heavy thing. But my right arm, elbow*

> *hurts too much. It is really bad. In short you bring pieces in your mind. I come to my doctor. I said this and that. The said it is muscle pain. Do you believe, it is healed? My other breast hurts, he say this and that. When he said it heals. You are psychologically affected from some things" [U3]*

Patient: U4 / Prototype: Paternalistic

Statement:

> *"I did not inspect them much. I am not spectical, but if I have trusted. I leave myself unconditionally to my doctor. It is the case with my surgeon. His hands are like a bird. When he touched, when he measured you can not understand. He speaks less. I mean, I do not want to tell stories for hours. Only main headings. For example before chemotreaphy first test are made. I asked how much time this will take. He answer it depends on ypu. It was weard at fisrt. But it is true. I am here in surgery by postponing 12 week chemotreaphy. Since it will be taken. However progress was soo god, they took me in surgery immidiatly. Now I had 3 month gain."*

Patient: U5 / Prototype: Mutual Decision Making

Statement:

> *"He help me to accept it easly. He said your breast would not be removed. But after MRs and all other things. He came before the surgery and said that my breast could be taken totally. But id I desire he said he can leave. Because his opinion is valuable for me I said take it. That make me little bit upset"*

Patient: U6 / Prototype: Mutual Decision Making

Statement:

> *"He can be competent in his domain, or somewhere else, but he might not answer your concerns. I believe that they are investigating all possibilities and offer best options to me. I can not say I know, it is not possible, but I believe. I am confident in that respect. I believe they work scientifically, in cooperation. As surgery, radiology, oncology I recognize that they work together. I have observe that it is not something that one person decides. I am confident in that manner. Because I know this job is not one person show, it is team work. I can observe that, I feel relaxed. I believe they will offer me the best thing."*

Patient: U7 / Prototype: Paternalistic

Statement:

> *"At first doctors standing, status gives you courage When you see him, there are some doctors, they have speak a lot but in fake manner. They say this and*

> *that but has no meaning. I believe he is serious, the one loves his job. I believe he does what ever is necessary“*

Patient: U8 / Prototype: Paternalistic

Statement

> *“I could not sleep until I have got surgery. But I got surgery I have opened my eyes. My doctor came, said have you checked the surgery place. I said not yet. He said raise you head, let me show you. He showed me the surgery place. He said you have overcome hardest part, next is easier. That was enough for me. I took drug now but I assume it is pain reliever. This is not disease for me. But I have overcome that shock. Now when I see this place I have remembered and cry. When I saw leaking from suture I cry. Nurses say do not cry we will recover them. Even this gives you a trust. I have unspoken words for the doctor who first gives me news. He ruins me really. I would say him look I have everything complete, next time first think then tell results to patients. “*

Patient: U9 / Prototype: Paternalistic

Statement:

> *“My doctor said: ‘results are bad. We do not get you stress by taking biopsy and waiting 20 days. We take it all. Anyway during surgery biopsy result will be taken. In the meantime result came immidiatly, then I can decide according to result.’ Result has been bad anyway. He take away totally, but with my approval. I said what ever happens, my breast is not important. As long as I have got well“*

Patient: U10 / Prototype: Mutual Decision Making

Statement:

> *“Doctor said my age is too young it is better to take all of it, it is risk of reoccurrence in future, and in other circumstances even if inside is taken in future there would be a second surgery. I said especially that I want to get into surgery once and get rid of it”*

Patient: S1 / Prototype: Absence of Relation

Patient: S2 / Prototype: Supplier

Statement:

> *“they said that we can not give drugs. They said that it has become smaller, it needs to be taken with surgery; doctors said it got smaller take it away”*

Patient: S3 / Prototype: Paternalistic

Statement:

> *"I have trusted. May be I have trusted because nothing bad happent to me, I do not know."[S3]*

Patient: S4 / Prototype: Absence of Relation

Patient: S5 / Prototype: Supplier

Statement:

> *"What should I have expect from doctor. He treats us, do not make something mean."*

Patient: S6 / Prototype: Supplier

Statement:

> *"Let me tell, biopsy result have been told to my husband, my husband did not told me, I learned in here. It was difficult for me, doctor told. I have breakdown, I cry. I ask for permission. I have persuaded by doctor. Doctor is persuaded to me and we did not go anywhere else. Diagnosis has taken in this hospital. We did surgery in here."*

Patient: S7 / Prototype: Absence of Relation

Patient: S8 / Prototype: Absence of Relation

Patient: S9 / Prototype: Supplier

Statement:

> *"I left to doctors, so we trust them and leave ourselves. We said what ever needed do that"*

Patient: S10 / Prototype: Supplier

Statement:

> *"They say to me you have first go, doctor said to you and you have expect. I say how many people is involve, every one tell something else, my mind twins, I could not decide to anyone. Best thing I trust my doctor. "*

4.4 Empowering Patient: Self and Information

In this chapter we will examine relations with self and information. Patient empowerment can be achieved through seeking information by using various sources, sharing this information with care givers, and using the obtain information in decision making processes. In this part we will examine patients' attitude towards different parts of empowerment. At the end of this chapter, we will discuss internet as an information source. And we will examine whether patients are accessing internet, how they use it, perceived accuracy of information, positive and negative effect to patients.

4.4.1 Information Seeking

Cancer diagnosis is dreadful experience for most of the patients. Women have difficulties in accepting the disease. Most of them do not want to talk or hear about anything on cancer. This behavior pattern leads patient to not seeking information on their diseases. In our interviews 8 women express explicitly their attitude towards not want to hear any information on cancer, 7 women does not any access to information, only 5 women gathers information from various sources.

4.4.1.1 Do not want to inform

Most of the women are unwilling to seek information for their disease. 8 of the 20 patients express that they do not want to seek any information on cancer. These were mostly upper middle class or middle class women living in urban areas.

Some of women think that having information might cause confusion for them. A retired nurse having breast cancer states that:

> *"As much as you learn more, thing get complicated. "[U1]*

Other women might feel anxiety and distress from the information they have learned. A middle class house wife expresses that:

> *"No no, I had apprehensions, I do not look"[U3]*

Some other women might think that talking and thinking on disease might harm their healing. A university graduated white color technical personnel states that:

> *"In reality I did not search on. Why ? Because I am not in the mood of own the disease. Disease is happened. Undoubtedly it happens from our inattention. Then it will go as if is come. I am getting the required treatments. I had a surgery. I am careful on my life quality. After that moment, there is no reason to stay with me. I have done for it goes away. Then I do not want to search a lot. I do not know. It seems unlikable. Because I do not want to stay with me, I do not want to posses it."[U4]*

Also many other women expressed their unwillingness to learn information on their diseases. [U7, U8; U9, S9, S10]. A 54 year old middle class housewife living in urban states that:

> *"I do not want to search on; I do not want to poke it. When doctor explain...I feel more relaxed in phchologically" [S9]*

4.4.1.2 No access to Information

Most of the lower class urban women or women from provinces or from rural areas have no access to information. In some cases they have no opportunity; in other cases they have no interest. They are perceiving doctors as only source of information.

A 43 year old woman from rural area expresses their lack of access as:

> *" We live in village. We do not watch television much. We work until night. "[S8]*

Another 46 year old lower middle class woman form Bolu, express their inadequacy to understand information and their information dependency to doctors:

> *"We do not know. What we will know from medicine. They tell a medication name.. if I had anything we do not understand we ask our son, we ask doctor when we went to. They are educated people, they are not like us primary school graduated"[S6]*

A 69 year old uneducated lower class women living in urban perceive that information seeking is doctors' duty:

> *"Doctors already know it. Now doctors are changed. They are more aware. And more over there are having meetings twice a week; they are given latest information to them. " [S3]*

In some cases patients suffer from lack of information. They expect to have information from doctor but they might not get. Husband of a breast cancer patient from rural area of Urfa uprising his complains:

> *"they do not give information. Last time I went to doctor 3,4 times they did not give any clear thing."[S7]*

4.4.1.3 Active Information Seeker

In our interviews, 5 of the 20 women actively seek information on their disease. 3 of these women were university graduated intellectuals; other 2 were young (below 35) house wife coming from other towns.

Some of the upper middle class highly educated women has been in risk group for breast cancer and actively seek for information before they have diagnosed. A university graduated white color worker states that:

> *"I have plenty of information on subject from Internet. Since I had fibrocystic surgery doctor said it was a risky situation. I know therefore."[U5]*

Another intellectual who have lost her mother from breast cancer express that she is searching information for a long time:

> *"It is on my mind more than 20 year. I can not forget for one second. [U6]*

Some other women start to seek for information after they have diagnosed. A young lower middle class woman from Kırıkkale begins to look for information for her disease:

> *"Yes we had many search in Internet. He (my husband) did too, he search too. I had search to learn what should I had to eat, what should I had to drink."[U10]*

Another young woman from Kütahya again actively searches for information with the help of her husband:

> *"My husband enters the Internet, he looks from there, what happens, why happens. Some say it is genetic. Everybody says something else. We do not search deeply, but just go and look"[S5]*

A 73 year old upper middle class woman delegate information seeking to her highly educated daughter and also keeps watching TV programs.

> *Her daughter: " (I search) from Internet ...I follow up her disease. Additionally she regular audience of health programs in TV" [U2]*

4.4.2 Information Sources

Women and their families learn about their disease from various sources. Main information sources are television, internet, neighbors and friends, hospital community groups. And also there are young children searching information for their mother's health.

4.4.2.1 Internet

All of the women who are actively seeking information use internet as a source of information, either by themselves or by the help of their relatives.

In interviews we asked patients where do they have obtain information on their diseases. All of the actively information seeking patients are mentioned internet as a main source.

> *"from Internet... [U2]*
>
> *"I use mainly American health associations web sites for obtaining information. [U6]*
>
> *""My husband enters the Internet, he looks from there, what happens, why happens. Some say it is genetic. Everybody says something else."[S5]*
>
> *"Yes we had many search in Internet. " [U10]*
>
> *"I have plenty of information on subject from Internet."[U5]*

4.4.2.2 Television

Television programs supply one of the main information sources for patients and their relatives.

Some upper and lower middle class women both from Ankara and other provinces mentioned television as a source of information:

> *"she regular audience of health programs in TV." [U2]*
>
> *"we watch TV."[S2]*
>
> *"I have watching TV programs, new diagnostic test are found.. "[U3]*
>
> *"Onlu doctors in TV especially him. Because he seems as the master of this domain from Istanbul, I pay attention to his discourse."[U9]*
>
> *"yes I have wacth. When I have seen news I did not skip. [U9]*

4.4.2.3 Health Care Personnel

Some women or their relatives supply information from health care givers other than their suppliers.

Some of patient obtains information from other health care professionals other than their providers.

> *"Since I have opinions of those who work in this job. Before chemotherapy our neighbor's sister in law brings me to here. My you might know. For example before I went to chemotherapy I asked her what kind of thing this is, is it serum or drug, what will happen when I take it"[U7]*
>
> *"We do not know. What we will know from medicine. They tell a medication name.. if I had anything we do not understand we ask our son, we ask doctor when we went to. They are educated people, they are not like us primary school graduated"[S6]*

4.4.2.4 Hospital Community

In hospital women establish a community. While they are waiting for encounters or for their medical procedures, they communicate with other patient and patient relatives. This community becomes a source of information for most of the women.

> *”We have a like a group, we come together in hospital”[U2]*
>
> *“I share and talk with those I have met in hospital. I do not take account on herbalists, folk medicine. I do not watch TV much”[S9]*
>
> *“When I went to doctor, I talked with other waiting patients, I got recommendation from them and they recommended my doctor. [S5]*

4.4.2.5 Neighbors and relatives

Neighbors and relatives are a source of information for some patients.

Friends and neighbors are an information source for middle class women:

> *Daughter: “Things those neighbors has succeeded.” Patient: “He makes surgery of a neighbor’s mother. In June. She has bypass, has diabetes, praise to be she is very well.”[U2]*
>
> *“I had a doctor neighbor in apartment, my friend. I show her. What can be this thing under my breast? She said this is not moving. Go to doctor. She had breast cancer 15 years ago. She said go to my doctor. I did”[U3]*

4.4.2.6 Young adult children’s

Young adult children’s of patients actively search for breast cancer information and become a source for women.

In all socio economic classes next generation search information for their mothers and grand mothers

> *Daughter: “They (Grandsons) say my mother to quit these drugs, otherwise your nerves will die, and you will not be able to walk.” Patient: “I say so, my son if it is true, doctor gives these medications, what kind of thing this is”[S3]*
>
> *“Before surgery we do not search at all. After surgery, my daughter still search. It has been three months. She keep searching (for information) For example last day she said to me, during chemotherapy you had to go in a*

> *scanning. In order to see whether remaining is growing or not. She says ask this. She always do that"[U9]*
>
> *"Last night a famous doctor was on television. My little daughter sits and watches after midnight".[U7]*
>
> *"My son is looked for me. He said I would not afraid. My doctor said also. It is seen in 90 of 100 women… we do not need to afraid."[S6]*

4.4.3 Information Sharing

Patient's tendency to share gathered information with their care givers varies. Some patients are openly sharing and asking their obtained information with their doctors, others ask questions but not get clear answers, and others are hiding their information from doctors because of they are discouraged or shy. Mostly middle class and upper middle class women share information with their doctors. None of the over middle aged lower class patients has information sharing experience.

4.4.3.1 Asking Questions

Only some of the patients can share the information that they have obtained with their doctors.

A highly educated patient relative can easily share her obtained information with physicians:

> *Daughter: "I ask. I copy all things; I ask doctors in these, I take their opinions. Since all of them are my friends I did not gat nay reactions. They explain to me. In there everyone said there is an age factor. Chemotheraphy and radiotheraphy could be difficult for her. But since I know my mother does not want I have asked in that way. When all doctors here agree on total…"[U2]*

A lower middle class young woman who has actively seeking information from internet does not hesitate to ask questions and get answers:

> *"I did not hesitate (to ask questions) Mostly when we asked in explanatory manner we did not have rude reactions. They explain in detail, understandable and clear manner. I asked whether breast cancer is genetic, or mother who gives breast feeding can caught to cancer. They said us it can*

> *be genetic but related with persons gene, it is not related with breast feeding."[U10]*

None of the over middle aged lower class patients state an information sharing experience with their doctor.

4.4.3.2 Do not really want Answers

Some of the middle class women ask questions related to their tumor types. Doctors were reluctant to answer questions, and women were happy to not get exact information.

A middle class woman searches her cancer grade and learns that there can be metastasis. She asks her surgeon whether it is true:

> *"I asked to my doctor. He said it is not true. He said what you say is stage 4. It is not happen in stage 3. "[U3]*

Then she had more questions but can not ask further:

> *"Yes, I said to my doctor…Professor..(stop and think) I can not ask him much… " [U3]*

Then she went to her radiology specialist and told the story:

> *"After all I went to radiology. I said to radiologist; I have learned from my surgeon it is jumping type, fast multiplying type. That is happened when he is renewing sutures. I said doctor I like to make prosthesis. He said do not do it. Your type is that" [U3]*

Her radiology specialist gave contradictory information:

> *"then I went to my radiologist. Radiologist said there is not need for ray. There is no metastasis in my under arms. I said this is the type of mine. He said no. Yours is the one %70 percent of women has. " [U3]*

Then she has decided to ask her another doctor:

> *"When I went to another doctor, I said I like to learn type of mine. You said to everyone, but not me. Everybody knows type of theirs. Jumping one, so on. Because I talk with patients. I talked with patients a lot. He said your is like that, but it is not a comparisons point. Since in some cases we say this does not jump, it jumps. But sometimes we say it jumps but nothing happens. No one can know it. When he says like that I feel relaxed. No body knows what will happen expect God. What will be what will not" [U3]*

All after her attempts she did not learn the type of her tumor, but feel relaxed and figure out that she do not need to know.

Another upper middle class university graduated woman ask her doctor the type of the tumor, however she is not very willing to hear information:

> *"For example I asked breast ca, I can not even say the name of the disease, what is the type of it, they have always asked to me. Doctor said what will happen when you learn? Is it so necessary to know? I said not so necessary but they have asked. Doctor reply as: oo say that I do not know my doctor knows, do not think on it. No need to learn. I said ok then. Later I have seen in my report it is grade 3. "[U4]*

Women feel more comfortable when they do not know exact diagnosis about their tumors.

4.4.3.3 Passive Observers: Hiding the Obtained Information

Some of the women hide their obtained information from their physicians for several reasons.

An upper middle class woman who actively seeks information hesitates to share her information with her doctor:

> *"I could not ask too much. Because the other doctor, doctors are some kind soo in this issue. They are uncomfortable with internet information. I could not ask from that. Bu as I speak to my doctor I figure out some internet information are correct."[U5]*

She uses obtained information for veriying doctor knowledge. But express that when she asks questions doctors are not like it:

> *"...But doctors mostly do not like from Internet, internet information… They say never mind. Because they can not convince you what they said. Sometimes you stick information from internet; in that case you do not believe what doctor says. "[U5]*

An intuallectual woman, do not approve to share her obtained information with the doctors. She respects the professional boundries:

> *"Not at all. It is not my specialty. I can not know this kind of thing. Every day they have many different type of patients. They know better. I am a scientist. Therefore interfering someone else job.. If some comes and thrust nose in my job I do not like either, so this people does not like it also "[U6]*

A lower middle class young woman seeks information from internet but she is to shy to share it with her doctors. She think that it is not proper to talk on her obtained information.

> *"we do not say anything like that (getting shy and smile)... when we say like that (again smiles) they say patient is clever dick, we do not want to make them say that. "[S5]*

4.4.4 Internet as a Source of Information

In this part of our research, we will examine how internet has been used by patients to gather information, what is the attitude towards internet gained knowledge, and what are the perceived advantages and drawbacks of internet usage from the perspective of patients.

4.4.4.1 Access of Internet

In our interview group access of internet significantly varied among University hospital patients and State Hospital Patients. 8 of 10 University hospital patients has internet access from home, where as only 3 of 10 State Hospital patients has access from home. None of the State Hospital patients use internet by them selves, whereas only 3 University hospital patients do not use internet. This difference caused from different socioeconomic status of patients. Some of the patients, even they do not use internet by themselves, they gather information by their husbands, sons, daughters, or grandchildren. Therefore we have analyzed internet access as by themselves and by others.

4.4.4.1.1 By Themselves

Some patients are stated that they are actively used internet to gather information on breast cancer. Upper middle class, highly educated women are more capable of using internet. On the other hand young women, below 35, intent to actively use internet independent from their socio economic status:

A university graduates white color worker woman from upper middle class:

> *"I have plenty of information on subject from Internet. Since I had fibrocystic surgery doctor said it was a risky situation. I know therefore."[U5]*

A young woman from lower middle class.

> *"Yes, we searched much from Internet." [U10]*

Some women, especially whose has high level of anxiety, do not gather internet information for their disease. A middle class woman, who use internet everyday for playing games, communicating, and entering virtual society, do not prefer to use internet for obtaining health information: She explains this behavior with a story refers to 'there is no disease but patient" metaphor:

> *"I use it (internet). But not for my disease. But now I come to doctor. I do not want to get confused. It do not know me. For example my child, when he was young used to get sick. He got tonsillitis. My husband was military officer. You keep moving city to city. At each time you explain child (to doctor). I know my child. How he is. If he has fever in afternoon aroun 36, 37 that night fever goes up to 40-41 for certain. I am not docotr. But I know. When I got at 3 o'clock noon, now in his throat, next in his liver, he used to gots bronchitis. I ws giving drug according to that. Something like that. Doctor knows me. He knows all test results. I do not need to ask someone else. I trust my docotr a lot, I like him very much"[U3]*

A retired nurse expresses same concern in different way:

> *"but you got too much confused, all these make you confused. I have experienced a lot. Each doctor practices differently. You live such a complications. I have trusted by doctor, I decide my direction, and has finished" [U1]*

An intellectual woman using internet everyday gathers information on breast cancer, but she has concerns on it:

> *“You got some information, but on the other side each day you look to internet and get demoralized. “[U6]*

A high school graduated upper middle class woman rejects internet because thinks that information should be personalized:

> *“I did not need. Because I have doubts on Internet can provide me accurate and clear information. Because people who are commenting they do not know me. I do not want to get afraid pointlessly. I can mind all these. I can not be sure how much is it true, how much is it not? But I can ask everything to my doctor. “ [U7]*

As a conclusion even in middle and upper middle class use internet for their everyday life, they have concerns using it for gathering cancer information.

4.4.4.1.2 By Others

Internet information is provided to patients even though they are not actively using it. In young generation young women with husband’s are seeking information on internet. Following two young women (below 35) use internet together with their familes:

> *“Not very often but I use as I needed. My husband uses, he is always on computer. We both, my sisters and brothers, (for learning) exactly what is it” .[U10]*
>
> *“at first I was curious. I said open it (internet). Sometimes he does, sometimes he does not. But for a long time I do not open. I follow treatment, keep coming here, what can I done more?”[S5]*

In lower and lower middle class children or close relatives are searching internet and try to provide information to patients. In following phrases, patients are worrying about their relatives:

> *“ After surgery, my daughter still search. It has been three months. She keep searching (for information) For example last day she said to me, during*

> *chemotherapy you had to go in a scanning. In order to see whether remaining is growing or not. She says ask this. She always do that. I say her do not think on it any more"[U9]*

> *"all my sister and brother are look (at the Internet). One of my sisters is midwife, other is teacher, other.. They have all got (computer) and they all look. They told me, they give me much information. When they have begun they have got upset too.* "[S8]

4.4.4.2 Usage Typologies

An upper middle class internet user patient describes how she has been using internet as below:

> *"you have entering to google as fibrocystic, then you look. I say symptoms of breast cancer. You say types. I have read by writing many different alternatives. It happens in what age. I seen more frequent in which stage. Which of seen more frequent? What are the signs? Which can cause? I read this type of things. I read a lot. "[U5]*

Some of the women state that they are searching information when they have a question or a related occasion:

> *Daughter: "I was not searching too much. When something happens to my friends, a disease, a thing I search on that issue. Just like my mom's example. What is happening? What kind of treatments. I look at large centers'. I thrust this hospital. I trust some of the doctors. I look their lecture notes. I look general information."[U2]*
>
> *"I have just look if something keeps my mind busy. Last time was about red blood cells related with chemotherapy. Why it decreases, how can be increase? How can I help to increase it, what can I do myself. Is there any food…At first I search for what is it then go to details. Is there any thing that I can do? "[U6]*

A lower middle class woman describes purpose of internet usage as follows:

> *"At first we have searched to learn what is breast cancer, what are reasons for it, what should or not should eat. Which doctors should we go, which of them are better, we search from internet. People around us start to give advices. When I have entered as breast cancer we were reading several sections, not any specific place." [U10]*

A lower middle class patient from provinces describes her and her husband’s way ıf using internet. They do not look for specific information, search for more popular sites:

> *“My husband enters the Internet, he looks from there, what happens, why happens. We do not search deeply, we just look. For example how general surgeon applies surgery on people. How is it resulted, what has happens. (My husband) do not open much. I want so, but he did not open much. He says thank to God it came and go. “[S5]*

One of the main internet usage type is young children information search and supporting their mother by saying that nothing to fear. However in some cases mother do not really pay attention to their attempts:

> *“My son is looked for me. He said I would not afraid. My doctor said also. It is seen in 90 of 100 women… we do not need to afraid.”[S6]*

> *“At first we have searched from internet. My son has been searched. Said mom this will not effect your life. HE enter web site but I d not know which one. He is medical personnel also. He said I will not afraid. But after third session it damaged my valve, my valves impaired again. Then I do not want to mention again. This will come with me and will go with me; I know it won’t kill me” [S6]*

> *“Children are look at the Internet. I was already aware of these. They said nothing to afraid mom. They make me feel relieved. Even they do look, I thought they do not understand. They have looked. But they do not insist.“[S9]*

4.4.4.3 Accuracy and Reliability Issues

Accuracy and reliability of internet information is widely discussed subject in many areas. Accuracy of given health information is more crucial from the other areas hence the indented population is very sensitive. Even though some of the information is not wrong, they can be disappointing for cancer patients. This may lead increase in anxiety, fear and loosing hope.

Among our interviewed patients some of the advance internet users think that internet information is valuable for them. They gather information selectively and refer more than one site for a information:

> *"...So in Internet I did not have ineffective information. I mean I did not see as inoperative. Of course I do not look all Internet information, only publications. When you look a few place, I found them mostly writing on Google, I have read publications, there were comment, doctor opinions, things that patients are written, there were answers that patients by doctors, there are a lot of things" [U5]*

On the other hand, other advance user might consider the possibility misleading information. She thinks that she does not have enough knowledge to interpret internet information to make conclusion.. However she find it very useful for learning medical terminology:

> *"I thing it can be misleading. Because my knowledge is not enough for it. I am not doctor. It is very questionable to use internet and drawn a conclusion with my superficial knowledge. For example I learn some terminology." [U6]*

Some other women more criticize internet, and only trust accredited sites for accurate information:

> *"I am against to internet in may respects. I am against to shopping from internet, related with health issues. Someone writes there that information. But chamber of physicians are trustable for me." [U4]*

In some cases women might be more reactive, possibly due to the their undesirable experiences, and reject internet information as a whole:

> *"no I did not enter Internet. It did not give correct information. None of them is correct in Internet for me. It is not healthy information. It confuses people's minds. Why we need it? You will trust your doctor. It is my opinion. "[U3]*

4.4.4.4 Internet as a Helping Process

We have interviewed breast cancer patient on their internet experiences. We have asked them to identify positive usages that they have experienced and facilitated their treatment. We have received limited number of positive responses. A young patient states that internet was partially useful. The gather information is helping them to understand disease and help to evaluate doctors:

> *“Partially, because we have understood what is it. First we understand what is breast cancer, how it happens. But most detail, most satisfactory information is given by the doctor in hospital. It has been enlightening that his explanation on why it happens and what can be happen.“ [U10]*

A patient family member states that internet was helpful for her to understand medical terminology and procedures:

> *Daughter: “Of course. Since I was not a doctor I did not know sentinel. I am searching it, how it is applied. I can close that subject”[U2]*

A mother receives information from her daughter about the lifestyle. She states that although information are accurate, she has already learned them from health care personnel.

> *“Of course. She said do not take weight. Drug will change that said. Do not take too much weight; do not give too much also. Be careful on your diet. Eat this and that. But I had same thing (information) here in hospital already. I was acting as if I do not know for not breaking the hearth of her. ”*

4.4.4.5 Saturation Point

Some women intensively use internet until one saturation point. Then they establish a trust relation with their care providers and do not need to search information from internet. A risk group upper middle class patient state that after long years of obtaining information from internet, she decided not to use it after her surgery:

> *"After the diagnosis I have shut down the Internet. I quit, never look. I do not want to be affected. What ever doctor says that's it. After I have come to my doctor, after surgery, after these sessions I do not open Internet. What ever it has been told I look just that. Because I have affected when I have open Internet. That's why I am not looking. There are also negative things in there, there are people who had treatment but spread out. I do not look for this reason. I have shut down Internet now" " [U5]*

Although against her decision, in some cases she gets curious and try to search, but then again drawback and close the internet:

> *"I look little bit again. I found a few words in pathology report. I try to look them. But I could not found. Then I have shouted down. Since I could not make it, I have closed. I said to my self what ever my doctor says I will do that. I decided to that. I do not look now. I do not look anything related to health." [U5]*

Patient state that she emotionally negatively effected, therefore she does not consider to use internet in future anything related with cancer.

> *"I think that I would not look anything related with this disease. Because I have affected. But I can look for other things."[U5]*

Another young patient again use internet until her surgery. After than she gets formal information from care provider and she do not need to use internet:

> *"I did not look for neither test results or after surgery. My husband does not look anymore too. I have read the entire book that nurses is provided. I know what can happen. I used Internet more often until surgery. For seeking doctor, try to learn what can be harmful".[U10]*

4.4.4.6 Internet as a source of Distress

In our research we have founded that breast cancer patient mostly disappointing experience to gather information from internet. Main reason of this frustrating experience is comparing their diagnosis or prognosis with others and fearing from possible outcomes. Most of breast cancer patients believe that their disease is not bad as others, by this way they keep their hopes alive and find encouragement to fight against cancer. Therefore doctors are reluctant to say tumor types to patients and patients are not willing to learn all details. Both doctors and patients believe that same tumor might have different prognosis in each patient, and prognosis is much more correlated with psychological condition of patient.

An upper middle class intellectual woman questions internet and underlines her limited access to scientific resources. She express that there are very contradictory resources and reading of them causes disappointment in to her:

> *"Is Internet is trustable? I mean web sides I have entered are trustable? There are plenty of things. Are there trustable things? Are they up to date? Are they current? We can not access all places. There are sources with limited access. I had search on Google. These are the sources that everyone can access. I am aware of it. How often they are updates? How accurate are they? There are many sources. Which one you will trust? These types of things are demoralizing for me. I can not estimate, with my current knowledge, is this my situation? I have other friends. They are looking foreign resources. I have heard same things from them. They say they have got demoralized, they do not look Internet much, and they do what doctors say. I am just trying to access certain sites. Related with foods, and on."[U6]*

Another patient argues that if you can find proper web sites by comparing them you can find correct information. But she underlines there are many exaggerations:

> *"If you have found appropriate web site it is true. But if you can not found, there are many exaggerations. They present you last stage of a disease, you have got break down. But you have to find appropriate sites, appropriate publications that require much research…There exaggerated ones. There is not accurate information. But when you find accurate information from a few different sites, you understand that it is true. You can filter and access accurate information"[U5]*

She cites her experience related with other disease and examples how she produce fears and negatively effected from internet information:

> *“What I have determined in internet is this, which is valid for some other disease also. A disease has certain prognosis, it has begin, progress and end. In some web sites, may be for taking attention or having loyalty of reader that first stages exaggerated. I mean, because I had a disease related with* osteoclasis. *I have searched in internet for that too. At the last stage bones are become bent, it got broken, you can not move for not breaking them. Doctor said to me I got beginning of* osteoclasis *since I am at certain age. But I got afraid. But those were long time ago in 97,99 Now Internet is better. More accurate information more correct information it supplies. “[U5]*

A retired nurse and breast cancer patient criticizes internet information. She thinks that it cause panic in patient, and this kind of patients creates difficulties both for their doctor and their family. She does not approve to patients take time of doctor with this kind of panic behaviors:

> *“There are many diseases with same symptoms. I have experienced in once. I says oh my god, is this diagnosis. It is very very rare. This can be diagnosed by doctor, not by you. There are a difference between knowing patient and not knowing one, but it also has disadvantages. Patient goes, says this and that, got panic. It is very bad if a patient gets panic. When she is panic she put pressure on her doctor. Giving and taking business gets harder. However in your communication when you look the eyes of your doctor he should understand what you have feeling.” [U1]*

Another lower middle class patient has been observing her daughters internet experience. She states that her daughter seen awful pictures and she does not approve her to search anything related with cancer:

> *“Yes. My daughter got too much afraid. She say to me if your hair does not fall of, I would not believe you are taking chemotherapy. She got to much scared. It is my fault. I happened suddenly without orientating. She saw the picture of people who gets chemotherapy. Those people got open wounds, swellings, black marks. There are corrosions. She got afraid. Now she promises to me she do not look any more that things. There is no need. If I live all these, I will. Why you are afraid. Let me live it. There can be information for noticing people. Do not get shock this and that will happen. But I do not want my daughter to enter there “[U9]*

4.4.5 Level of Empowerment

Patients' level of empowerment is categorized into three groups by Knoop and her friends: Accepting, involve and in control. Definitions of these types given as follows:

> "Accepting. These patients rely almost entirely on doctors for health information and decisions.
>
> Informed. These patients also rely on doctors to make decisions but typically go online to learn more about a diagnosis or prescribed treatment without, in their view, wasting the doctor's time with questions.
>
> Involved. These patients view themselves as partners with their physicians in making health care decisions. Before and after visits, they seek information online to discuss with their doctors; but they still rely on them to make the ultimate decisions.
>
> In Control. These patients believe that they are best suited to determine their own care. They use online information to diagnose their conditions before visits, determine which treatments they want, and persuade their doctors to treat them accordingly." [44]

Patient: U1 / Level of Empowerment: Informed

Statement:

> *"People do not know their legal rights. For example I have encounter with a doctor last day. He treats me badly. I said I am withdrawing you. I am changing to another doctor immediately. But I know these. They do not have right to make all these to those poor people. I am against it." [U1]*

Patient: U2 / Level of Empowerment: Informed

Statement:

> *Daughter: "Some times I might have a contradictory idea with doctors. For example I heard possibility of sentimentally giving drugs to lymph nodes. But our doctor was against it. I still wonder could it be better. My mom insists on. But during encounter I was not there. Doctor said it is not reliable. "*
>
> *Patient:" I am convinced. I did not want to go in surgery again and again. I can be difficult for me. Even though at the beginning I prefer sentimental I said ok, do what ever doctor prefers. "[U2]*

Patient: U3/ Level of Empowerment: Accepting

Statement:

> *"I did not let anyone to interfere. No body knows better than doctor. I even do not know type of my disease until now. When I ask, they do not give clear answers. Both my oncologist and surgeon. They have said after the surgery. I did not seek for information. After surgery I have no power. What will be changed if I have learned_ Nothing will be changed." [U3]*

Patient: U4 / Level of Empowerment: Accepting

Statement:

> *".... I am not spectical, but if I have trusted. I leave myself unconditionally to my doctor. ..."[U4]*

Patient: U5/ Level of Empowerment: Informed

Statement:

> *" He said do not thing anymore. They do not want you to get apprehensions in this disease. They say do not mind, if it happens we take care of it. For example I have asked will I take chemotherapy. I was too much afraid of it. He said never mind. There is plenty of time for it. After 15 days I was in chemotherapy. I was relief physiologically. He suddenly takes film after the surgery. My feed was holding back, I came. The make me to get chemotherapy appointment at a sudden. He makes me to easily accept, make easier for me."[U5]*

Patient: U6/ Level of Empowerment: Involved

Statement:

> *"My friends husband, other things in internet, I know it. I search as far as I can. I am not doctor. From the beginning a weird thought has been clarief as keeping my body as a whole, not separating parts as far as possible. I try to protect as it is possible. They have give me option."[U6]*

Patient: U7/ Level of Empowerment: Accepting

Statement:

> *"That is my principle in life. Who ever is the master I have done what ever he said. When I bought a close, where is the best one sold, I take from there. I*

> *feel safer. Moreover we think to ask opinions of our friends. We figure out having opinion of acquaintance doctors, time was 10, 11 at night. My husband went at that time and got learn all. He came home and told me. Then we decide that why should we bother to get biopsy, run after pathology. Instead of having trouble two times it is better to go surgery immediately" [U7]*

Patient: U8/ Level of Empowerment: Accepting

Statement:

> *"Tedavi ile radyoterapi de görürsün senin kurtulma şansın çok çok yüksek dedi doktor bana. O zaman hocam benim sağlığım için ne gerekli ise onu yapın dedim........ Doktor güzelce muayene etti baktı demek ki almayı uygun gördü ki aldılar. Şimdi de burada bunu aldılar. Geçecek. ……..Radyoterapiyi söylediler o erken daha sen kemoterapine bir başla dedi. " [U8]*

Patient: U9/ Level of Empowerment: Accepting

Statement:

> *"I can make doctors to listen to me. By forcing. Of course my doctor is a good person. I am very pleased from him. He already explains everything to me. He said during surgery if these and these happen I did that, if those happen I will decide, remove partially. Otherwise I will take totally. I mean after surgery I did not have shock. I knew already."[U9]*

Patient: U10/ Level of Empowerment: Accepting

Statement:

> *"I want to get rid of them before they have spread out. Doctors told me they had to remove urgently. Friday we went, they said Monday remove it. It was in short time. When they say urgent, we can not know in a sudden. We decide to come here. " [U10]*

Patient: S3 / Level of Empowerment: Accepting

Statement:

> *"We done what ever doctors say. Do not get medications with our own will" [S3]*

Patient: S5/ Level of Empowerment: Accepting

Statement:

> *"I am very pleased from my doctor, god be pleased with him, did nothing to me, he take me in surgery between, It is already late he said. It was not my surgery day but I had to take you in emergency"*

Patient: S6/ Level of Empowerment: Accepting

Statement:

> *"There was issue of trusting doctor. I did it in here. I do not need to look other options. Because my doctor is said so. If he sends me to home, he knew I will go to other places. He said 6 month passes until you decide. It is possibility to spread out." [S6]*

Patient: S9/ Level of Empowerment: Accepting

Statement:

> *"When pathology result is arrived, I was continuously crying. I was nervous. Doctor said to me lets talk you are so nervous. He called me to his room. He explained to me by drawing. He said there is an insect there. He said it is upon you to remove it completely or only remove cysts. I said to him, what I can tell; you do what ever is needed. "[S9]*

Patient: S10/ Level of Empowerment: Accepting

Statement:

> *"I was aware of many things since I am a medical personel. At first I have reacted but then.." [S10]*

A subgroup of accepting behavior can be defined for lower socio economic status and rural area comers. In this category we can discuss that these patient neither in awareness of diagnostic procedures not consider different treatment options. Rather that being an actor in health care delivery they are more subject of care. They are dealing with physical difficulties of disease and treatment process.

Subject: [S1], [S2], [S4], [S7], [S8]

CHAPTER 5

DISCUSSION AND CONCLUSION

In this study we have examined self and self relation with disease, health care system, and information to cope with health care processes.

Firstly, we have analyzed self and disease and questioned how patients react when they have encounter with cancer. There are three main dimension of relation between self and disease: conceptualization of cancer, coping mechanisms and interdependently constructing self. Figure 3, show these dimensions and concepts related to with these dimensions.

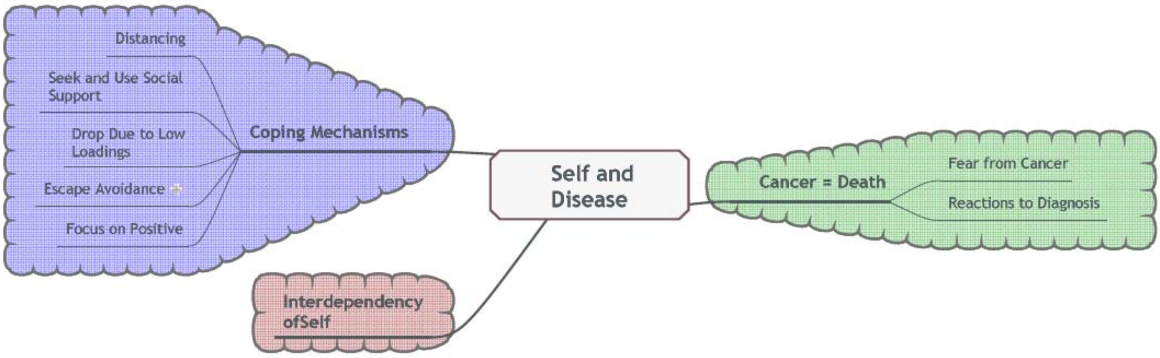

Figure 3: Dimensions of self and disease

Since death is highly associated with cancer, fear, stress and anxiety was the main psychological factors that patients have to deal with. In some cases fear from cancer appears even before patients were diagnosed. When they have informed with diagnosis, many women has difficulties in accepting it. Although lower middle class and less educated women are more likely express their feelings, most of the woman express the relation of death and cancer, and were distress by having diagnosed with this disease.

There is several coping mechanism for patients to cope with cancer. These coping mechanisms both have psychosocial impact of prognosis of disease and also influences the patient empowerment. There are two extreme sides patient appear to abdicate personal control, they may feel completely helpless, deny the seriousness of the disease, delegate all decision making powers for health care to medical stuff and exhibit regressive models of behaviors in family. On the other side patient may seek to increase control over their lives by learning specific illness related procedures for caring for themselves, setting self improvement goals to overcome any disabilities caused by their illness, and seeking relevant medical information that will enable them to evaluate and choose between courses of treatment.

In our analysis we observe that patients develop one or more of the following coping mechanisms:

- Cognitive Escape-Avoidance: Wishes the situation would go away, slept more than usual, so on.
- Behavioral Escape Avoidance: tried to make myself better by eating, drinking, drug use, so on.
- Distancing: went on as if it were not happening, tried to keep my feelings my self, tried to forget whole thing, kept others from knowing bad things, so on.
- Focus on the Positive: Found new faith, changes something about my self
- Dropped Due to low loadings: the only thing to was wait, so on.
- Seek and Use Social Support: try to find as much as I could, talk to someone about how feeling, so on.

Table 10 show how our interviewed women are cope with the cancer and their socioeconomic status. In our analysis distancing is seem to be more common mechanism in middle class where as drop due to low loadings appear as lower class mechanism to cope with cancer.

Table 10: Coping Mechanisms of Women and Their Socio Economic Status

Coping Mechanisms	Patient	Socio Economic Status
Seek and Use Social Support	U1	lower middle class, nurse
Cognitive Escape-Avoidance	U4	Upper middle class, white color worker, university graduated
	U3	Middle class house wife, high school graduated
Behavioral Escape-Avoidance	U1	lower middle class, nurse
	U5	Upper Middle Class, University, white color worker
Distancing:	S9	Lower Middle Class from Ankara, house wife
	U3	Middle class house wife, high school
	S6	Lower Middle Class, from Bolu, House wife
	U6	Upper Middle Class, Intellectual
Focus on Positive	U4	Upper middle class, white color worker, university graduated
	U1	lower middle class, nurse
Dropped due to low loadings	S1	Lower Class, primary school, informal sector
	S7	Lower Class, Rural area
	S8	Lower Class, Rural area
	S10	Lower Middle Class, nurse

In our study we have analyzed women's experiences in terms of individualist and collectivist self constructs. Most of the women take their medical decision collectively, and they are also experience anxiety to not being accomplished their social roles in family. Also most of the middle class prefer to hide their disease from their children in order to preserve their role in family. Some of the lower class women experience concerns related to being a burden for family, and some others has shamed from being ill since they are woman.

Secondly, in our study we have analyzed patients' relation with health care system. Figure 4 presents dimensions of our anlaysis.

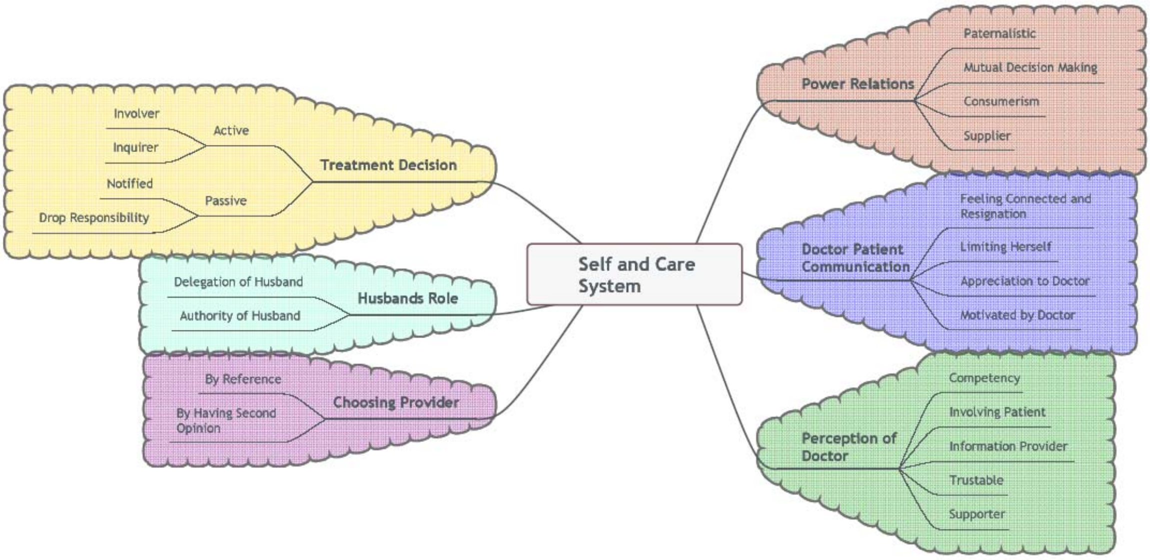

Figure 4: Dimensions of self and health care system

First we have analyzed how patients describe qualifications of good doctor. Competency, involving patients, providing information, being trustable and providing support is mentioned as required qualifications of a doctor. Table 11 presents how patients are perceived a good doctor.

Table 11: Patients Perception for Qualification of Good Doctor

Qualifications of Good Doctor	Patients	Interpretation
Competency	U2, S3	Old Patients
Involving Patient	U6	Intellectual
Provide Information	S9, S6, S7, S8	Lower Class
Trustable	U4, U8, U3	Middle Class
Supporter	U5, U7, U9, S10, S1, S5	Common for all Classes

Professional competency of doctor is mentioned by two old women as a basic factor. These patients were the oldest patients in our interview sample. Because of their ages, they might not directly relate breast cancer with death. Therefore rather than psychological factor, they have focus on achieving best care possible.

Involving decision processes is important for empowered patients. However in cancer patient’s willingness to participate decision making is not common. In our interviews only one patient was willing to declare her preferences to her doctor and involve decision process. This was an intellectual woman who takes active participation in decisions and highest empowerment level.

Most of the State hospital patient expressed their expectations of information from their providers. Providing information is appeared as most important qualification of a good doctor for them. These can be precedent by several reasons. First of all State Hospital patients are socioeconomically from lower and lower middle class, most of them came from rural areas and do not has access to information sources such as internet, informative documentations, so on. Even though they can access they do not have enough infrastructure to interpret obtained information. Secondly, they are more drawing more clear lines between themselves and professional knowledge. Most of the patients do not interest diagnostic procedures and details of their diagnosis, or treatment alternatives, rather they consider reflection of disease on their bodies. Having information is the first step of patient empowerment. Women from lower class have lock of information. They expect doctors to provide information to them.

Middle class women emphasized trust ability as a main qualification for a doctor. For them trusting their doctor is vital for receiving a good treatment. Most of their doctors also believe that trust of patient facilities the doctor patient communication, and even with absence of trust successful treatment process can not be accomplished.

Importance of doctors’ supporter role was mentioned almost by all patients from all socio economic classes.

Another questioned was how patients have been choosing their providers. We observe that having second opinion is very is very common behavior among University Hospital patients. However, one of the active information seekers has been used internet information to decide her provider together with references personally known.

Husbands also play important role relationship of self with care system. Most of the middle class women are willingly delegating power to their husbands because of their fears. However in lower class authority to get information and make decisions is in husbands rather than women. Husband play dual role. For rural lower class they have authority and they make decisions for women. For middle class, they are delegated by their wife as a buffer for their fears.

When we analyzed doctor patient communication we have observed four main typologies. Most of the middle class women from University Hospital express that they feel that they can ask any think to their doctors, even if it is not the case. And they withdraw from taking responsibility for their care process. In these cases women do not or can not ask question related to diagnosis or treatment, rather they have consult for outcomes or preventive measures. In next typology women restricts themselves because of inexplict unbalanced power relations. Another result of the unbalanced power is feeling appreciation to doctor as default behaviour.

Last subject of self and care system dimension was analyzing power relations between patient and doctor. In University Hospital doctors has high power. When patients do not empowered relation paternalistic relation type is observed. When patients are empowered a mutual decision making is observed. All mutual decision makers in University Hospital were same time active information seekers in internet. In state hospital both patients and doctors has low power so relation type, if it is exist, was supplier relation. Table 12 presents power relations between patient and doctors.

Table 12: Power Relations between Patient and Doctors.

Power Relations	Patients
Paternalistic	U1, U3, U4, U7, U8, U9, S3
Mutual Decision Making	U2, U5, U6, U10
Supplier	S2, S5, S6, S9, 10
Absence of Relation	S1, S4, S7, S8,

Secondly, in our study we have analyzed patients' relation with information. Figure 5 presents dimensions of our anlaysis.

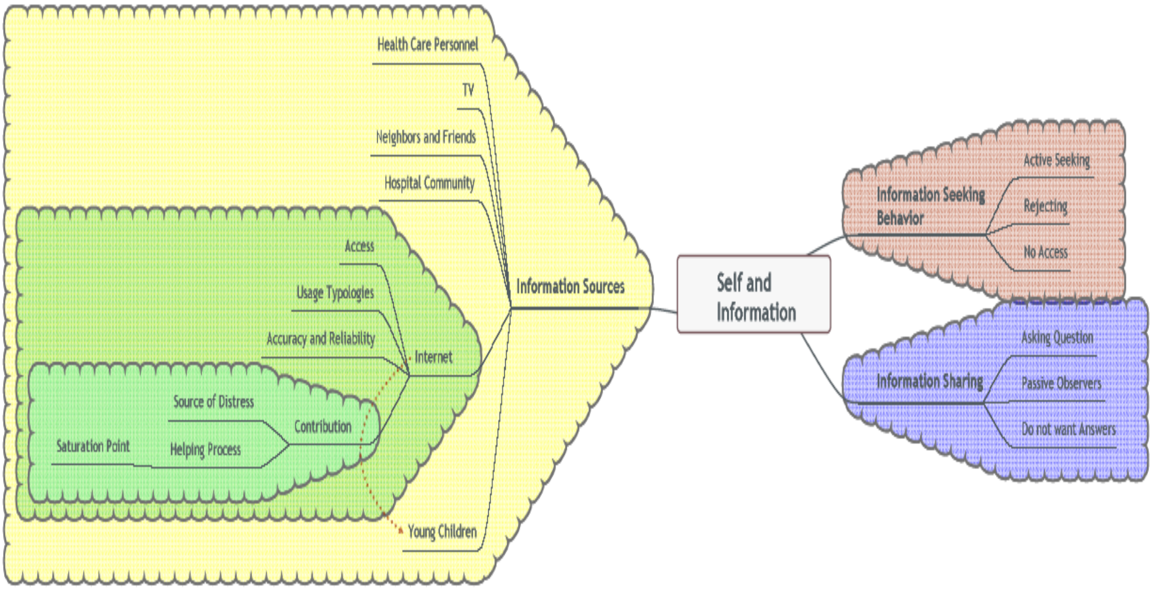

Figure 5: Dimensions of self and information

In this part we first analyzed patients' attitude towards having information. First step of patient empowerment is accessing the information. Table 13 shows patients' information seeking behavior.

Most of the women are unwilling to seek information for their disease. 8 of the 20 patients express that they do not want to seek any information on cancer. These were mostly upper middle class or middle class women living in urban areas. Most of the middle class women have fear, they neither want to have information nor get involve in decision making.

Most of the lower class urban women or women from provinces or from rural areas have no access to information. In some cases they have no opportunity; in other cases they have no interest. For lower class and rural areas accessing information is limited, even if they have access they can not interpret it.

In our interviews, 5 of the 20 women actively seek information on their disease. 3 of these women were university graduated intellectuals; other 2 were young (below 35) house wife coming from other towns. Young generation regardless of their socio economic situation, are using internet and getting empowered.

Table 13: Information Seeking Behavior of Patients

Information Seeking Behavior	Patients	Interpretation
Active Seeking	U5, U6, U10, S5, U2: proxy	Young generation & Highly educated upper middle class
Rejecting	U1, U3, U4, U7, U8, U9, S9, S10	Middle Class
No Access	S1, S2, S3, S4, S6, S7, S8	Lower Class

There are many source of information. Table 14 presents these forms. TV is most predominant source. Also for middle and lower middle class women, young children plays important role for collecting and sharing information with their mothers.

Table 14: Source of Information

Information Sources	Patients	Interpretation
Internet	U2, S5, U6, U10, U5	
TV	U2, S2, U3, U7, U9	
H.C. Personnel	S6, U7	
Hospital Community	U1, S9, S5	
Neighbors and Friends	U2, U3	
Young Children	S3, U9, S6, U7	Middle and Lower Middle Class Families

Next step of patient empowerment is sharing and discussion information with provider. Table 15 presents how patients shared their gathered information with their doctors. Only some of the patients can share the information that they have obtained with their doctors. Most of them act as passive observers and hide their obtained information from their doctors’. They use obtained information for verifying doctor knowledge. Most of the middle class women feel more comfortable when they do not know exact diagnosis about their tumors. They do not ask questions related to their tumor types, so on. Even they ask doctors were reluctant to answer questions, and women were happy to not get exact information.

Table 15: Information sharing levels of Patients

Information Sharing	Patients
Asking Questions	U2, U10
Passive Observers	U5, U6, S5
Do not Want Answers	U3, U4

If we inspect usage of Internet we observed that women might access internet by themselves of with the help of others.

Some patients are stated that they are actively used internet to gather information on breast cancer. Upper middle class, highly educated women are more capable of using internet. On the other hand young women, below 35, intent to actively use internet independent from their socio economic status

Internet information is provided to patients even though they are not actively using it. In young generation young women with husbands are seeking information on internet.

Patients concerns with accuracy and reliability of internet.

Among our interviewed patients some of the advance internet users think that internet information is valuable for them. They gather information selectively and refer more than one site for information. On the other hand, other advance user might consider the possibility misleading information. She thinks that she does not have enough knowledge to interpret internet information to make conclusion... However she found it very useful for learning medical terminology. In some cases women might be more reactive, possibly due to their undesirable experiences, and reject internet information as a whole.

Next we have analyzed that whether patients found Internet beneficial or not. Some patients also state that internet was partially useful. The gather information is helping them to understand disease and help to evaluate doctors. Again a family member states that internet was helpful for her to understand medical terminology and procedures.

However, for all internet users we observed that they have reached a saturation point. When they make decision and trust their doctors, they are avoiding search for information on internet.

In our research we have founded that breast cancer patient mostly disappointing experience to gather information from internet. Main reason of this frustrating experience is comparing their diagnosis or prognosis with others and fearing from possible outcomes. Most of breast cancer patients believe that their disease is not bad as others, by this way they keep their hopes alive and find encouragement to fight against cancer.

Lastly we examined level of empowerment of patients. Table 16 presents the results. Most of the patients are classified as accepting; neither has informed nor wants to get empowered. Some of highly educated upper middle class women are informed and achived the first level of patient empowerment. But only one patient is involved in decision making processes.

Table 16: Patients' Level of Empowerment

Level of Empowerment	Patients
Accepting	U3, U4, U7, U8, U9, U10, S3, S5, S6, S9; S10
Informed	U1, U2, U5
Involved	U6
Subject	S1, S2, S4, S7, S8

Some of upper middle class, high education women use internet intensively, and want to involve in decision. However most of them can not take responsibility, and leave decision to the doctor.

Patients prefer to seek for information until they made a decision, mostly deciding a doctor. Then they tent to trust their doctors without inquiring. Basically, information utilized for finding right doctor.

In some cases, empowerment do not improve outcome. 4 of women out of 20 we have interviewed report that even they know what they shall do, they do not regularly have their controls and missed the early detection change.

In short we can conclude on patient empowerment in breast cancer patients as follows:

- Fearing from disease is an important factor that hinders patient empowerment.
- Different coping mechanism might lead different empowerment levels.
- In University hospital setting patients has access to internet but not always willing to use for searching disease related information.
- Middle class patients are refusing to seek information on their disease.
- Husbands has active role in health care delivery process in lower middle class and lower class.
- In lower middle class women are tent to willingly delegate power to their husband.
- In some of the lower class husbands authority to manage health care processes.
- Patients are mainly accepting in their relations with their doctors.
- Most of the informed patients are not willing to share their knowledge with their doctor.
- Patient do not involve in their treatment decision even they are informed.

5.1 Conclusion

This study will contribute to understand changing nature of patient physician relationships with patient empowerment. Patient empowerment is a focus in health care domain since mid 70’s. However, with widespread use of information and communication technologies internet informed patient concept has been raised. In last two decades, Internet becomes a main source of information in many countries. Health related information can be easily accessed by non professionals. This new motivation leads patient empowerment to a new area and has strong impacts on physician patient relationship. Patient empowerment within the scope of information communication technologies are not studied with all aspects. Our research will contribute the literature by illuminating changing patient physician relationship.

In this study as results of our analysis we have reached following conclusions:

- Most of the middle class women has fear, they neither want to have information nor get involve in decision making
- For lower class and rural areas accessing information is limited, even if they have access they can not interpret it
- Young generation regardless of their socio economic situation, are using internet and getting empowered.
- Some of upper middle class, high education women use internet intensively, and want to involve in decision. However most of them can not take responsibility, and leave decision to the doctor.
- Most of empowered patients do not share their information with physicians. They use this information to test doctor.
- Patients prefer to seek for information until they made a decision, mostly deciding a doctor. Then they tent to trust their doctors without inquiring. Basically, information utilized for finding right doctor.
- In some cases, empowerment do not improve outcome. 4 of women out of 20 we have interviewed report that even they know what they shall do, they do not regularly have their controls and missed the early detection change.
- Husband play dual role. For rural lower class they have authority and they make decisions for women. For middle class, they are delegated by their wife as a buffer for their fears.

Health system reforms, carried out by many countries, are reshaping health care delivery system. Empowered patient emerge as demand side of these new system. Focusing only supply side and reorganizing the distribution of health resources, without recognizing how empowered patient will impact the health care processes, will be a deficiency in attaining desired effective health care provision.

This study examines effects of empowered patient in patient-physician relations which is the core of care processes. Outcomes of this study should be considered in all countries which are conducting health care reforms and promoting patient empowerment.

5.2 Limitations and Further Studies

This study has limited with breast cancer patients. Brest cancer has limitations due to the associated fears, anxieties and believes. Also age group is older than many other diseases. These are all factor that limits patient empowerments. This study can be enhancing to other disease groups and results can be analyses comparatively.

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Appendix A: PATIENT LIST

	Abbreviation	**Description** **(age, education, occupation, marital status, class, residence, health care supplier)**
Patient 1	U1	Age: 50-59; College graduated; Nurse; Divorced; lower middle class; Ankara; Lower Middle Class (metropolitan); University Hospital
Patient 2	U2	Age: 70+; High School graduated; House Wife; Married; Ankara; Upper Middle Class; University Hospital
Patient 3	U3	Age: 50-59; High School graduated; House Wife; Divorced; Ankara; Upper Middle Class; University Hospital
Patient 4	U4	Age: 50-59; University graduated; Technical Personnel; Divorced; Ankara; Upper Middle Class; University Hospital
Patient 5	U5	Age: 50-59;University graduated; Technical Personnel; Married; Ankara; Upper Middle Class; University Hospital
Patient 6	U6	Age: 36-39 ;University graduated; Academic Personnel; Married; Ankara; Upper Middle Class; University Hospital
Patient 7	U7	Age: 40-49;High School graduated; House Wife; Married; Ankara; Upper Middle Class; University

		Hospital
Patient 8	U8	Age: 50-59;High School graduated; House Wife; Married; Ankara; Lower Middle Class (metropolitan) ; University Hospital
Patient 9	U9	Age: 40-49;High School graduated; House Wife; Married; Ankara; Lower Middle Class (metropolitan); University Hospital
Patient 10	U10	Age: 30-35;High School graduated; House Wife; Married; Other Provinces; Lower Middle Class (towns) ; University Hospital
Patient 11	S1	Age: 50-59;Primary School graduated; Informal Sector; Single; Ankara; Lower Class (metropolitan); State Hospital
Patient 12	S2	Age: 60-69;Primary School graduated; House Wife; Married¸ Other Provinces; Lower Middle Class (towns) ; State Hospital
Patient 13	S3	Age: 60-69;Primary School graduated; Informal Sector; Widow; Ankara; Lower Class (metropolitan) ; State Hospital
Patient 14	S4	Age: 50-59;Primary School graduated; House Wife; Married; Other Provinces; Lower Class (towns) ; State Hospital
Patient 15	S5	Age: 30-35;High School graduated; House Wife; Married; Other Provinces; Lower Middle Class (towns) ; State Hospital
Patient	S6	Age: 40-49;High School graduated; House Wife;

16		Married; Other Provinces; Lower Middle Class (towns) ; State Hospital
Patient 17	S7	Age: 36-39;Primary School graduated; Farmer; Married; Rural Area; Lower Class (Rural) ; State Hospital
Patient 18	S8	Age: 40-49;Primary School graduated; Farmer; Married; Rural Area; Lower Class (Rural) ; State Hospital
Patient 19	S9	Age: 50-59;High School graduated; House Wife; Married; Ankara; Lower Middle Class (metropolitan) ; State Hospital
Patient 20	S10	Age: 50-59;High School graduated; Nurse; Married; Ankara; Lower Middle Class (metropolitan) ; State Hospital

Data Ranges:

Age: 30-35; 36-39; 40-49; 50-59; 60-69; 70+

Education: primary, high school, university,

Occupation: house wife, nurse, technical personnel, academic personnel, informal sector, farmer

Marital status: single, married, divorced, widow

Residence: urban, rural, towns

Class: lower, lower middle, upper middle

Health Care Provider: State Hospital; University Hospital