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**Listening to Women:
Political Narratives of Breast
Cancer in Spain**

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Submitted for the Degree of Doctor of Philosophy in Social Anthropology

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I hereby declare that this thesis has not been and will not be, submitted in whole or in part to another University for the award of any other degree.

Signature: _____

Abstract

The thesis examines the complex relationship between individual experiences of breast cancer and the wider social, political and discursive context in which they are located. It focuses on how Spanish women living with breast cancer define their own health priorities by exploring their experiences and their dissatisfactions, which appear to have been excluded from public and biomedical discourses. The data was collected in a provincial city in Western Spain and focused on the lived experiences of 32 women living and surviving breast cancer. Interviews were mainly conducted in the headquarters of the Spanish Association against Cancer of that region, but also at women's homes and in other public spaces. Based upon a framework of narratives of resistance, grounded in feminist theory, critical medical anthropology and sociology, an ethnographic approach allowed a focus on breast cancer patients and survivors as 'experts' of their own health, addressing fundamental concerns in the production of knowledge. The thesis discusses the relationship between breast cancer and social inequality. It examines the dramatic ways that structures of power such as class, age, gender, and disability, intersect and "conspire" through a web of social beliefs, practices, norms and expectations to shape, and exacerbate, women's experiences of illness, in particular, of those women who need health care the most. The research also highlights the ways in which the experiential symptoms of breast cancer are portrayed and perceived in public and medical discourses in sexual terms or physiological terms, which ignores the wider social and embodied contexts of women's experiences. By answering the call made by feminist writers such as Wilkinson (2001) and Broom (2000) to listening to the narratives of resistance of these Spanish women, this study therefore offers both a particular cultural account of their collaboration with a range of institutions such as health professionals, charities, the family and the social care system, but also valuable lay experiences which are more generally relevant to wider healthcare practice and policy.

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List of Acronyms

ACs	Autonomous Communities
AECC	Spanish Association against Cancer
ALND	Axillary Lymph Node Dissection
CAM	Complementary and Alternative Medicine
CE	The Spanish Constitution (<i>Constitución Española</i>)
ECSNS	Strategy against Cancer of the National Health System (<i>Estrategia en Cáncer del Sistema Nacional de Salud</i>)
FECMA	The Spanish Federation of Breast Cancer (<i>Federación Española de Asociaciones de Cáncer de Mama</i>)
FESEO	Spanish Federation of Oncology Societies (<i>Federación de Sociedades Españolas de Oncología</i>)
GP	General Practitioner
LCCNHS	Law on Cohesion and Quality of the NHS (<i>Ley de Cohesión y Calidad del NHS</i>)
LD Flap	Latissimus Dorsi Flap
MSC	Ministry of Health (<i>Ministerio de Sanidad y Consumo</i>)
NHS	National Health System
SLNB	Selective Lymph Node Biopsy
TRAM Flap	Pedicled Transverse Rectus Abdominus Myocutaneous Flap

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Prologue and Overview of the Thesis

Why Breast Cancer

This thesis is about the lives of breast cancer patients and survivors in Spain, which appear to have been excluded from consideration and investigation. I attempt to explore how the material, social, emotional and historical circumstances of their lives intersect to shape their experience of illness. Although there are a myriad of works on breast cancer, to my knowledge there is no anthropological research on the lives of Spanish breast cancer patients within the context of their daily existence.

This thesis emerged out of an intuition that much of the public discourses on breast cancer in Spain are focused on the “sexual” (Saywell, Beattie and Henderson 2000) aspects of the disease, such as how mastectomy (italicized terms are defined in the glossary) violates women’s femininity, how it impacts on women’s body image, or on their sexual relationships. I began thinking of the problems I had with this emphasis and I found the scene upsetting. As cultural stereotypes of the duped woman who is anxious about her breast, and myths about the ideal woman, turned into a powerful discourse about breast cancer, I thought it reinforced normative ideals rather than enabled women to come to terms with the loss of the mindful breast, their changing bodies, or the prospect of death.

With these concerns in mind I enrolled in a MA program in Women’s Studies at the University of York in 2005. That was when I first discovered the fascinating and provoking feminist debates on breast prosthesis, breast reconstruction, and “pink culture”, which questioned the diverse interests articulated around the “ideologies of breast cancer” (Potts 2000a) that I will present in Chapter 2. However, when I was researching for my MA thesis I began thinking of the inadequacies I felt were present within the same feminist literature that had illuminated and inspired me during that year. I thought that the excessive focus on attacking the sexist nature of breast cancer discourses distracted the focus from what actual women with breast cancer may think was important. I also thought that these feminist discourses ended up reproducing the ideological bias which reduces women to their breasts. Thus, the more I read the works

of Sue Wilkinson and Celia Kitzinger (1993, 1994) extolling the importance of asking breast cancer patients about their health priorities, rather than assuming that we know more about their needs than they do, the more I wanted to embark on an anthropological project about the experiences of Spanish breast cancer patients from the perspective of women themselves.

At the beginning of my research for this thesis, I must admit that the concept of “social inequality” was not consciously articulated in my thinking. It was in the course of this project, however, that I have been struck by the extent that I missed seeing women’s experiences of breast cancer framed in terms of social inequality.

Ongoing fieldwork, but especially political, visceral and passionate women’s narratives, allowed me better to understand complex accounts of inequality. Since I started, I have learned the subtle and violent forms of inequality which occur when age and social class intersect with women’s historical trajectories and major structural forces like the health system or the labour market, to produce and reproduce social inequality in breast cancer experiences. Women decried that in many cases it was not only the physical problem of cancer, but the injustices of the society, which affected them mentally, physically and emotionally the most. Women spoke about their fears concerning their prospects for employment which were jeopardized by the disabling effects of cancer treatments and extended sickness leaves, they spoke about the complex nature of their social networks which were sometimes helpful but sometimes a burden which impeded them from taking rest. Of course, they also spoke about their health concerns and how often these were ignored, minimised, infantilised, and attributed to everything being “in the woman head”.

Thus, this thesis is not only interested in enumerating what happens to women. It is also concerned with the structural violence(s) associated with the processes by which social inequality operates and is (re)produced, in order to influence those processes and improve the delivery of health services for breast cancer patients.

Nonetheless, given my determination to represent women’s concerns, I am aware that I have a tendency to portray a dim picture of women’s lives which prevents me from presenting the more positive aspects of their experiences of breast cancer. However, this picture is a critical matter for the purposes of this project since it engages the questions of resistance (Wilkinson 2001; Wilkinson and Celia Kitzinger 1993, 1994) and “realizing rights” (Cornwall and Welbourn 2002). Therefore, I hope that this thesis

is not read solely as a criticism of the inadequacies of the Spanish social structure, but as a unique opportunity to reflect aloud about breast cancer patients and survivors's "aspirations, wants, preferences, choices and calculations" (Appadurai 2004: 67). It is my hope that these aspirations can open up useful new research avenues which are obligatory for further deepening our comprehension of how a disease such as breast cancer exacerbates and reproduces social inequality. Furthermore, these aspirations encourage a coordinated collaboration between different institutions working on breast cancer, including health professionals, charities, social scientists, social networks, policy makers, and of course, women themselves, if we are to improve the well-being of breast cancer patients and survivors.

Aims of the Thesis

This thesis aims to respond to Laura Potts' (2000a) call for an examination of current discourses and practices around breast cancer in order to understand the experiences of breast cancer patients. As we shall see in Chapter 2, the most vociferous discourses customarily are medical discourses. In fact, discourses on breast cancer remain the monopoly of biomedicine. Increasingly, however, social scientists and breast cancer survivors, usually health professionals and academics (Couser 1997: 38), have begun to shift this discursive perspective to foregrounding the social dimensions of breast cancer, rather than treating it as a merely biomedical disease.

This shift is consistent with, and draws on, an abundance of research and theory generated in anthropology (Jain 2007; Hunt 2000), medical sociology (Hallowell 1998, 1999, 2000; Green, Griffiths and Bendelow 2001), cultural studies (Sedgwick 1994), literary studies (Epstein 1996), philosophy (Young 1990), nursing studies (Im and Lee 2002; Im and Hautman 2000) and social psychology (Wilkinson 2000a, 2000b, 2001). The most significant contribution of this thesis is found not only in the attention to the social aspects of breast cancer, but in the acknowledgement that the "missing" discourses are to be found among the breast cancer patients themselves. That is, the chief inspiration for this thesis is the conviction that the narratives of Spanish breast cancer patients are an essential component in understanding the complex social forces that have informed what we know about breast cancer, but more importantly, "what we do not know" about it (Ferguson and Kasper 2000: 2).

In trying to address the missing “competing” discourses, vital to understanding the entire picture of breast cancer, breast cancer patients’ voices can and must be heard using a narrative approach (see Wilkinson and Kitzinger 1993, 1994; Wilkinson 2001; Broom 2001). One of the inherent methodological issues in the application of a narrative approach to addressing the problem of (lack of) representation, is that it has to employ a framework which assumes breast cancer patients’ experiences are a legitimate form of knowledge. Following that, the application of a critical medical and feminist approach to the use of narratives demonstrates how women’s experiences are powerful “method[s] of discovering society [which] restores her to a center which in this enterprise at least is wholly hers” (Smith 1987: 85). Yet, a narrative approach requires reflexivity to consider how the dynamics of power relations within the research relationship shape the narrative encounter as much as what is heard (Mauthner 1998; Garro and Mattingly 2000b; Fairhead and Leach 1997). I will address these key methodological issues in Chapter 3.

Throughout this research, I was aware that I was studying a group of Spanish women who, perhaps, only had in common the experience of living with breast cancer. I was aware of rich discourses based on autobiographical work (e.g. Broom 2001; Durán 2003; Lorde 1997; Matuschka 2003, 1994, 1997a, 1997b; Picardie 1998; Spence 1988; Knaul 2008), as well as provocative academic discourses on breast cancer which warned me of the need to listen to women in order to deepen our understanding of the politics of breast cancer (Wilkinson and Kitzinger 1993, 1994, 2000; Wilkinson 2001, 2000a, 2000b, 2000c; Potts 2000a; Kasper and Ferguson 2000; Kaufert 1996, 1998). I shall explore this rich literature in Chapter 2.

Although I was aware too of some important and inspiring works which used a narrative approach, I was drawn to this approach by two main facts. First, by the lack of narrative research on breast cancer in Spain, with the only exception I could find being Enric C. Sumalla Gómez’s work (2010) on “Restitution Narratives and Biomedical Discourses on Breast Cancer in Spain”.

Second, as narratives are appropriate for uncovering themes like identity (Mathieson and Stam 1995), impact of treatments (Thomas-MacLean 2004), the impact of mastectomy on body image (Langellier and Sullivan 1998), the experiences of coming to terms with the illness (Mathews, Lannin and Mitchell 1994) or emic understandings of cancer causation (Hunt 1998; Moore 2001), there has been a tendency

to neglect how breast cancer patients “generate the problems” (Smith 1987). In other words, this body of narrative literature revealed the subject matter of investigation was determined more by the researcher’s assumptions or values (e.g. what the researcher thinks it is more relevant) than by breast cancer patients’ “agendas”.

My work is based on the theory described by Sue Wilkinson (2001) as “breast cancer narratives of resistance”. She argues that exploring women’s narratives of resistance are essential in the research on breast cancer for three main reasons. First of all because it enables women to make sense of the experience of illness. Second, and fundamental for this thesis, because women’s knowledge of breast cancer, legitimated by their embodied experiences, is a powerful tool to challenge dominant biomedical discourses. Third, because women’s narratives of resistance allow us to see the structural forces “which frame the availability of choices and treatments for cancer” (Wilkinson and Kitinger 1993: 235). On the basis of this, I felt that a narrative approach to inform the understanding of breast cancer is obligatory. In particular, my research aims to hear, for the first time, the discourses of resistance from Spanish breast cancer patients’ points of view.

In the last few decades the use of narratives by medical anthropologists and medical sociologists has generated a wealth of academic work. Instead of at looking at illness from a positivist approach that “treats social facts as things” (Bocock 1992: 236) or which treats individual accounts of health as “disembodied” (Shore 1996: 54 in Garro and Mattingly 2000: 20) “realistic descriptions” (Riessman 1993: 4), social scientists working on health discovered that the use of narratives opened a window into how people experienced and interpreted their health and illness. That is to say, narratives allowed researchers to achieve a unique window into patients’ subjective experience of illness because, as Kleinman indicates, the experience of suffering can only be understood by talking to those who are suffering (Kleinman 1988, 1992, 1995a, 1995b).

Narratives enable the listener-reader to “empathetically” (Kleinman 1988) penetrate the private and subjective experience of illness which is difficult to grasp by other methods of data collection or epistemological positioning. This power of narratives to (re)present pain and suffering lies in its describable-conscious-vivid-viscerality which has the potential to provoke sensory responses in the audience (Langer 1953 in Garro and Mattingly 2000: 11). As Brodwin has so brilliantly shown in her work exploring how suffering reveals some of the qualities of a human language:

[Narratives] reveal the creative ability of certain people to convey a visceral sense of their suffering through a well chosen phrase (...) to express through a common language the private and wordless reality of chronic pain (Brodwin 1992: 77).

Narratives about health and illness are also narratives about society. They are a powerful resource to learn about the “gritty realities of social structure and social change” (Williams 2004: 279; see also Charmaz 1999; del Vecchio Good et al. 1994). This facilitates the task of making visible wider the social, political and discursive contexts in which the experiences of breast cancer are located, which are often overlooked by health professionals, the media and the family. In addition, I am aware that attending to the complex influence of the historico-socio-political milieu of women’s biographies, along with women’s narratives, is a must if I am to “anchor experiences in a robust way in social structure” (Dreier 2000: 254), or in other words, if I am to provide a “generous contextualization” (Razack 1998 in Dossa 2009).

There are other equally important theoretical trans-disciplinary contributions derived from the application of a narrative approach to the understanding of Spanish breast cancer patients’ experiences which have also informed this thesis. These contributions subscribe to a view of narratives as “agentic” (Esteban Galarza 2004) or as a “micropolitical tool” (Hunt 2000). Not surprisingly, therefore, narratives of illness and health have been defined as “methodologically dialogical” (Frank 2000: 354 in Thomas 2010: 653) or non accidentally political. Their political or agentic nature has to do with their therapeutic power, empowering potential, and resistance quality. This is not to say, however, that narratives cannot be used to disempower people too, as has been widely denounced by feminists writers (Smith 1987; Harding 1991) or by scholars working in the anthropology of development (see Stirrat 2000; Crewe and Harrison 1988). As Bell hooks (1994: 61) put it, narrative fulfills its constructive functions “when we ask that it do so and direct our theorizing towards this end”.

A very important contribution of the use of narratives is their therapeutic power. Garro and Mattingly (2000: 1) describe narratives as a “fundamental human way of giving meaning to experience”. The onset of cancer is an externally and violently imposed identity (e.g. patient vs. mother/wife/worker; disabled vs. able-bodied). This

means that the very reflexive-agentic-retrospective act of telling about one's subjective and personal experience can be healing because it may facilitate women's process of coming to terms with and making sense of their illness (Jones and Bunton 2004; Byrne 2003). The intense experience of making sense of one's illness often involves a unique healing process of (re)constructing one's identity, threatened by "regimes of treatments, changing bodies and disrupted lives" (Mathieson and Stam 1995: 284).

Another advantage of narratives are their empowering effect. For example, Rosaldo (1986: 98 in Garro and Mattingly 2000: 11) argues that narratives empower people by enabling them to tell their stories from the inside (e.g. as they really think and feel). This issue is, if anything, very important for this thesis because often women's narratives of breast "are at the margin of medicine" (Kleinman 1995: 195) and society (Couser 1997), as the lack of social research on the experiences of Spanish breast cancer demonstrates. In *Theory as Liberatory Practice*, Bell hooks masterly explains how theory (understood as the personal process of narrating her experience), was at once therapeutic and empowering because it allowed her to make sense of what caused her pain:

I came to theory because I was hurting, the pain within me was so intense that I could not go on living. I came to theory desperate, wanting to comprehend - to grasp what was happening around and within me. Most importantly, I wanted to make the hurt go away. I saw in theory then a location for healing (hooks 1994: 5).

A Spanish ethnography employing a narrative approach in describing the therapeutic and empowering effects of telling stories is found in Marta Aullé Martínez's (1996) autobiographical writing about her disability. At the age of 34 the author suffered a tragic accident which burnt 80% of her body. Although she tells about her social, physical, familiar and emotional suffering, her account is not one of victimization. She takes her narrative as an opportunity to recount the violent processes involved in her recovery, yet, she reflects simultaneously on the transformative strategies and abilities gained in the extreme process of learning the lessons of what becoming disabled can entail for a young woman in Spain.

A third strength already mentioned above looks at narratives as resistance. This scholarship acknowledges the significance of narrative as a process and agent of meaning-making in the context of unequal power relationships between the person and the world surrounding that person (Wilkinson 2001). This is illustrated in Linda M. Hunt's work, in examining the illness narratives of Mexican patients. She notes that narratives are a "micropolitical tool" which, in the ongoing process of coming to terms with their disrupted identities, enables patients to legitimate "the disjuncture between personal experiences [e.g. disability] and normative expectations [e.g. resuming sexual life]" (Hunt 2000: 100).

Through this quality, I aimed to explore not only whether there was a dissonance between the values attributed to women's experiences and those of women themselves, but how women come to terms with the violent structural forces that are weighing down heavily on their experiences of inequality and injustice (see Barakat and Wardell 2000; Hegde 2009; Spence 1988), thus challenging our thinking of how "things" matter to them.

For example, the assumption that the main issue of concern for women is the way in which breast cancer mutilates women's femininity, has been integral to the majority of research on breast cancer (e.g. Schon 1968; Christensen 1983; Ganz et al. 1999; Meyerowitz et al. 1999). This assumption was transferred directly into contemporary research, social activism and health policy. Subsequently, researchers and society are mostly concerned about traumatic experiences of baldness (Rosman 2004; Frith, Harcourt and Fussell 2007; Hansen 2007), or the impact of mastectomy on women's self-esteem, and how this impacts on their husbands' sexual desire and frequency of intercourse (Manos et al. 2005; Bartmann and Roberto 1996; Fobair et al. 2006; Harcourt and Frith 2008; Schover 1991). Less attention has been given on how women define their own sexuality (Wilkinson and Kitzinger 1994, 1993; Young 1990) or their health priorities. Indeed, my research findings challenge these assumptions and invite an "undefinition" (Hite 1993: 33) of women's sexuality. In other words, narratives of resistance help to minimize the researcher's power, in the form of assumptions, stereotypes, generalizations, victimization or ethnocentrism, over the data (Abu-Lughod 2002; Esteban Galarza 2006).

Esteban Galarza's (2004: 54) ethnography of corporal itineraries views narratives of the body as mindful actions which "reflect upon, resist, contest, change and subvert"

social structures and social expectations. Drawing on her work, and focusing on cultures of pregnancy in Tarragona, Montes Ruíz (2007) explores how all her informants resisted to some degree the process of medicalization which controls their bodies and fuels dependence on the system. This resistance operates at two levels. First, through redefining, questioning, and reconstructing cultural representations of pregnancy. Second, through small subversive strategies which challenged hegemonic practices and expectations. For example, some healthy pregnant women whose pregnancy was not at risk opted for home birth in an effort to recover control over their bodies and their reproduction. Not following the recommended practices prescribed by health professionals, or substituting them for different ones, were common strategies to recover control over their pregnancy when women's embodied experience and cultural knowledge clashed with biomedical dictates.

Whilst one of the dangers of a narrative approach is the risk of credibility of data given that stories are socially constructed for particular audiences with particular goals in mind (Wikan 2000: 320), I do not see this necessarily as a problem. Indeed, my fieldwork demonstrated that my research indeed became a "micro-political" tool to serve my informants' agendas. This point was made explicit, as much as implicit, by all the women throughout the interviews. I argue that in the context of this thesis, the assertion that research is a political tool for informants is benign. Women participated in my research not just to "pay off" a moral debt to the Spanish Association against Cancer (AECC) as I will explain in Chapter 5, but because my research inspired images of social justice. According to women, speaking out was the conscious embodiment of their common desire for social and health betterment. At the same time, the reflexive process of narrating provided a powerful lens (re)presenting the structural violences of their situation, and this thus helped women to (re)define the focus of their anger, pain, and prospects of future, as well as question and challenge dominant discourses and practices.

I anticipate that a potential criticism of this approach lies in the recognition of women as producers of knowledge. Therefore, given the exploratory nature of this study which seeks to investigate how women define their health priorities, I must consequently accept that "generalizations" made in this thesis can only ever be considered as "an epidemiological tool" guiding further investigation. Length and time restrictions, and the awareness of the danger of slipping into a unmanageable project,

frustratingly restricted my ability to expand on each of my findings with further interviews. Interestingly, Reisinger (2004: 242) argues that “epidemiology grounds the possibilities; ethnography stretches them”. While I agree with Reisinger, I argue that in the context of this thesis the reverse has happened: it is women who “generate[d] problems requiring sociological explanation” (Smith 1987: 84). In other words, narratives of resistance have “ground[ed] the possibilities” for future research by identifying new factors which I will explain in the subsequent chapters.

To sum up, two critical interwoven issues quickly become apparent when considering Laura Potts (2000a) call for attention to examine the current discourses and practices around breast cancer. First, the lack of discourses from Spanish breast cancer patients. Second, the importance of listening “empathetically” to women if we are to avoid exacerbating their invisibility. Therefore, a narrative approach not only provides a theoretical framework for the integration of women’s lived experiences of breast cancer, but is also a new opportunity for social sciences to deepen our understanding of the phenomenon of breast cancer. It is interested in how women “generate problems requiring sociological explanation” (Smith 1987: 84). It captures the indescribability of pain and suffering. It allows for women to agentically employ narratives as a therapeutic tool and as discursive “micro-political” manifesto to challenge biomedical and social assumptions. It sheds light on how the experiences of breast cancer are embodied and structured by complex socio-political and economical processes which are invisible to “outsiders”.

Outline of the Thesis

In Chapter 1, I present an overview of the landscape of breast cancer in Spain, setting the ethnographic context. First, I present some information on who gets breast cancer. Then I summarize the characteristics of women who participated in this study. I also describe the principles and organization of the Spanish National Health System and the Strategy against Cancer of the National Health System (*Estrategia en Cáncer del Sistema Nacional de Salud*, ECSNS). This is extremely important as I posit that breast cancer is an example of the inverse care law whereby social inequality operates at all levels of the social structure, including the health system. This happens despite several important factors: First, Spain has one the best free and universal health care systems in

Europe. Second, Spain has invested enormous resources in developing the ECSNS in an attempt to coordinate research initiatives and cancer resources in the country to guarantee the highest quality of cancer care for all citizens regardless their place of residence. Third, Spanish society is characterized by extended social networks indispensable for giving additional support. Then I introduce the AECC because it is Spain's leading charity providing the psychological and social care for cancer patients that the NHS fails to offer, and because it made this research possible. In describing this context, I hope to facilitate understanding of the social factors relevant to shaping Spanish women's experiences of breast cancer.

In Chapter 2, I am concerned with the various theories relevant to our understanding of breast cancer. I review the literature on breast cancer which resonates with the findings discussed in Chapter 4, 5 and 6. First I examine, and criticise, biomedical discourses on breast cancer which are characterized by a focus on the observable physiological dysfunctions of the body. Then, I discuss some of the literature which highlights the importance of looking at how social forces or "axes of difference" (Yuval-Davis 2006 in Davis 2008: 68) such as age, gender, and class, intersect to shape access to resources and the quality of care that patients receive. Finally, I review the tensions between biomedical and feminist understandings of breast cancer. I discuss why lay knowledge, or women's embodied experiences of breast cancer, are essential to challenge dominant biomedical discourses.

In Chapter 3, I describe my methodology. My concern is with contributing to academic knowledge while representing women's voices. I begin by explaining my epistemological position(s) which set the foundation for my research, and the collection and analysis of data. I reflect on the difficulties I experienced in getting access into the field; how I chose the sample; and how certain characteristics of the field limited my access to informants. Finally I explore how I came to realize my class (un)consciousness when I listened to women's accounts.

In Chapter 4, by presenting the stories of 3 informants I attempt to show how breast cancer affects women's (un)employability and how this increases their vulnerability to, for example, emotional distress, access to resources, and poverty. I explore the complex connections between patients' personal trajectories, women's differential access to financial resources, either through work in the paid labour market or through the state social care system, and social inequality. I examine how being in a position of social

inequality means that having breast cancer is more likely to make women's economic position worse. A vulnerable economic position has a clear potential to disrupt family functioning, burn out social networks, constrain social participation and leisure, which in turn increase women's chances of developing psychological and physical health problems, and social isolation.

In Chapter 5, I explore how inequalities of the social structure are produced and reproduced through the practices and attitudes of women, their families, their friends, and other social networks such as the AECC and 'the street'. First I explore how women define social networks. Then I attempt to show how social networks, which are considered as paramount to women's well-being, can also mask unhealthy normative patterns that are both enabling and constraining, therapeutic and stressful.

In Chapter 6, I investigate the relationship between women's access to treatments, social inequality and agency by examining two "hidden" dimensions of treatments relevant to women. I reflect on how in the process of narrating their (dis)embodied experiences with treatments, women "realized rights" (Cornwall and Welbourn 2002) and questioned the authority of biomedicine to define their health. Then I attempt to identify why these two important dimensions have been violently excluded from consideration and investigation. Firstly, I explore the significance of axillary lymph node dissection (ALND) or armpit surgery, and try to put into words the unspeakable nature of women's pain. I also examine women's criticisms of the routine use of ALND. Secondly, I examine the impact of treatments on women's mechanical sexual functioning, and how it affects women's ability to have erotic thoughts and even reach orgasms. I then examine the importance of the mindful breast for women's erotic and embodied pleasure. This chapter offers additional evidence of the challenges that lack of breast cancer units pose in relation to the achievement of the ECSNS's goals.

In the conclusion to this study I reflect on the contributions of my findings.

Chapter 1

The Context

1.1. Introduction

This chapter is concerned with presenting the social and cultural context in which women's experiences are located. In order to understand my informants' positions in contemporary Spain, as well as their lived experiences and the burdens of breast cancer described in subsequent chapters, it is a must to look at their narratives along the political and social dimensions in which their experiences are framed. Thus, before embarking on an anthropological examination of how Spanish women living with breast cancer define their own health priorities and experience breast cancer, it is essential to provide an overview of the landscape of breast cancer in Spain.

This chapter is divided in three sections. In the first part I examine the prevalence of breast cancer in Spain. I try to present some information on who gets breast cancer. Then I present the characteristics of women who participated in this study. In the second section, I focus on the Spanish National Health System, some distinctive features and its organization. I also explain how the ECSNS was born in an attempt to address some of the problems in the provision of cancer services that surfaced a consequence of the decentralization of the NHS. Indeed, the ECSNS main goal was to coordinate research efforts, provision of services and guidelines in care to guarantee equity in oncology. As I will illustrate in Chapter 6, this is extremely important as there is a correlation between the decentralization of the NHS, the ECSNS and women's unequal access to resources and treatments, and individual experiences of breast cancer (see Hahn 1995; Fassin 2004). Finally, I present the AECC, both because it is Spain's leading charity providing the psychological care that the NHS fails to offer, and because it made this research possible. It helped me to contact women who were willing to talk about their experiences of breast cancer, and provided a "safe" space for women in which I could carry out interviews.

1.2. Breast Cancer in Spain

This thesis faced major difficulties in portraying the situation concerning breast cancer in Spain. This was firstly because of the difficulty I experienced in accessing materials published on the issue, and secondly because there are many gaps in the literature itself. The tendency for researchers to conflate breast cancer with a homogenous group of women may partially account for these omissions. There is an underlying assumption that breast cancer affects only “classless” young Spanish-born women, who are white (i.e. of non-immigrant descent) and/or *Payas*¹ (non-*Gitanas*² or non-Gypsy). There are important exceptions, however, as evident in the work of Álcara et al. (2006), Francisco Polledo et al. (1998) and Masuet et al. (2004), which notes the influence of different axes of difference like social class and geographical location on screening participation.

These omissions within the published material not only pose a problem for my research which considers the significance of axes of difference for a social analysis of breast cancer. It also reveals some of the epistemological and methodological problems in public health, epidemiology, and more recently, attempts by the NHS, the Autonomous Communities (ACs) and the ECSNS to account for the multiplicity of ways in which forms of inequality are a barrier to a more egalitarian, effective provision of cancer services. Indeed, according to Borrell et al. (2004a), the majority of health plans commissioned by the ACs do not include any objectives addressed at tackling inequalities in health and, further, there are few examples of research and clinical practice that take inequality into account at all.

1.2.1. Prevalence of Breast Cancer in Spain

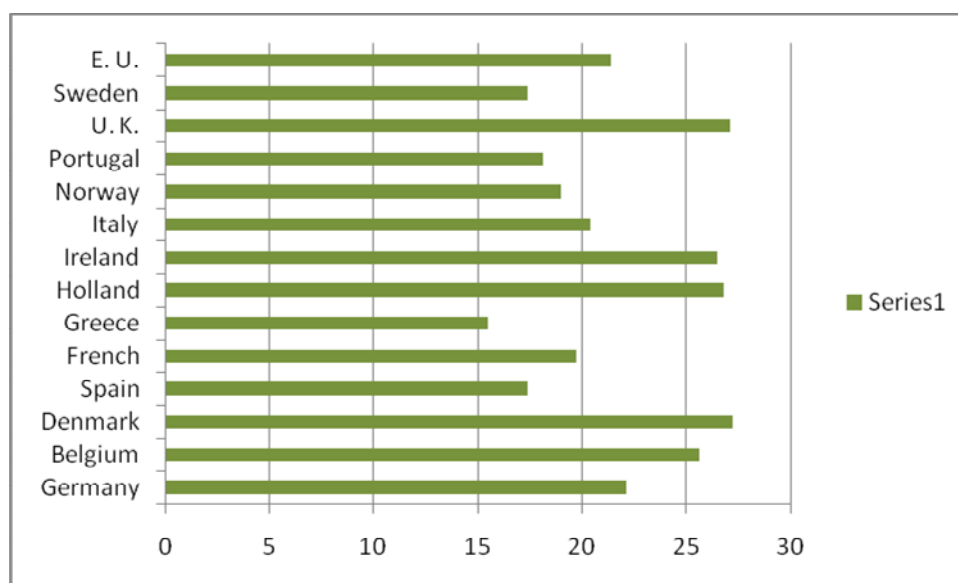
Around 430,000 new cases of female breast cancer are diagnosed every year in Europe of which 16,000 cases are diagnosed in Spain. Although Spain has one of the lowest rates of breast cancer incidence in comparison to other European Countries (Figure 1), it

¹ “Spanish Gypsies or *Gitanos* construct their distinctive way of life and their understanding of themselves as a group different from the non-Gypsies - whom they call *Payos* (payas for females)” (Gay y Blasco 1999: 3).

² According to Miguel Laparra Navarro (2005: 3) the word *Gitano* (Gypsy), and not Roma, is the appropriate word to refer to the Spanish Roma because “the Gitano community proudly name and identify itself as such”. This political definition is elegantly encapsulated by Juan de Dios Ramírez Heredia (2005), renowned *Gitano* activist and politician: “to be *Gitano* is to feel *Gitano*”.

receives as much media and public attention as in the UK or North America and has become a national health concern. Having said that, further research on breast cancer is necessary because it is a part of Spanish experience. In other words, an ageing population, compounded with improvement of survival rates due to advancements in diagnosis and treatment, have increased significantly not only the number of breast cancer patients but also of survivors, affecting thousands of women and their families, and putting heavy demands on the health and social services.

Figure 1 Number of cases of breast cancer in Spain and Europe



Source: (Catalá Institut d'Oncologia 2001: 12)

Breast cancer in Spain occurs mainly between the ages of 45 and 65. It is the most common cause of death in women aged 55- 64 (Artazcoz et al. 2004). Survival rates have improved significantly in the last decade and are superior to the European average. With 9,814 breast cancer patients surviving every year, it is estimated that 78% of women diagnosed will live more than 5 years (AECC, 2007a, 2008a).

Despite these general statistics, I could not find any work which analyses the incidence of breast cancer among racial/ethnic groups or by social class. The possibility that there may be differences in breast cancer incidence between ACs is however mentioned tangentially by some studies. For example, a review by Artazcoz et al. (2004: 63) points out that the highest incidence is in Catalonia and the lowest incidence rates are in Galicia and East Andalucía, yet their review does not provide any

information on how geographic differences³ may affect the probability of developing breast cancer, let alone an analysis of how incidence might be influenced by the intersection of age, region, social class, ethnicity or nationality.

1.2.2. The Sample

The women represented in this thesis are self-selected. Women learnt about my project through online forums, and through a letter that the AECC Carolina sent to all of its members. Voluntarily, they decided to give their time to participate in my research.

A total of 32 white Spanish-born *payas* breast cancer survivors and patients at various stages of the disease participated. 23 women were married or living with their partners; 6 women were single at the time of the interview; 2 were widows; 3 were divorced. Only one of my informants defined herself openly as a lesbian.

I recruited 7 women from online forums; 1 woman responded to the snowball email; and the remaining 24 women were contacted through the AECC.

At the time of the interview, 14 women could be defined as survivors as they had passed the “official” five-year period post diagnosis and treatments. 17 women were receiving some form of treatment at the time of the interview (e.g. chemotherapy, radiotherapy, surgery, reconstructive surgery or hormone-therapy). Although the majority of the women had undergone armpit surgery or ALND to determine whether the cancer had spread beyond the breast tissue, only 4 women had developed lymphedema. The women interviewed ranged in age from 37 to 80 years. The average age was 51.

Of all women, 17 were active employees⁴. That is to say, they were working *in the labour market*, actively seeking a job, or on sick leave. The remaining 15 women worked at home in the domestic sphere. All the women who were active employees had experienced short or prolonged periods of unemployment at some time or another during the treatment process. Just 4 women received disability benefits as a consequence of cancer treatments or surgery. Of these, 3 women were granted total permanent disability, 1 was granted absolute permanent disability, and another was

³ Geographic disparities in health are associated with multiple factors including environmental degradation, and availability and quality of material and infrastructural public resources (like schools, reliable transport, health services, social services or jobs).

⁴ According to Human Resources at Seattle University (2009) active employees are those who “are working on regularly assigned or scheduled days”

appealing her case in the tribunals. The definitions and meaning of these concepts will be explored in Chapter 6.

Only 4 women had university degrees, 9 women had college level or professional training as, for example, auxiliary nurse or hairdresser. One of my informants was illiterate but was attending a school for adult education. The remaining women had basic levels of secondary education. As we will see throughout this thesis, income significantly mattered to patients when it came to breast cancer: not only in terms of having access to leisure, complementary and alternative medicine (CAM⁵), or domestic workers to help with the burden of housework, but also in order to “make ends meet” (e.g. pay bills, rent, mortgage, children’s education and the like). Education level was also relevant to the way in which women interacted with and were treated within biomedical institutions.

All women had strong confidence in the NHS. In fact, 28 women underwent their treatments in the public sector. Just 3 women sought treatment in the private sector and 1 woman refused to have conventional treatment and was being treated with CAM. However, these 4 women returned to the NHS at some points during their treatments to minimize expenditure.

I conducted 22 interviews in an office provided by *la Asociación*. Of the remaining, 6 were in women’s homes, and 4 were in a coffee shop. All interviews were tape-recorded with participants’ verbal and signed permission, and later transcribed. Interviews lasted between one to three hours. If we ran out of time we arranged another interview for when it was most convenient for the woman. I also conducted informal interviews with three oncologists, the head of Carolina’s palliative care unit, several nurses, and two psychologists. I also had e-discussions with two gynaecologists who helped me to unravel and understand the complexities of women’s sexualities and breast cancer treatments.

By the end of fieldwork in August 2008, after several e-discussions with my supervisors, I decided to conduct formal interviews with some relatives of women affected with breast cancer. In this instance I decided to try to do my final interviews in AECC Zaragoza where I am from. At this stage of my research, I knew that I could get

⁵ CAM involves the practice of using non conventional therapies in combination with Western medical care (Tripathy 2002: 10-11.)

positive recommendations from Carolina and that this would allow me to overcome the initial scepticism that my research incited, as described in Chapter 3. Besides, it would be easier to avoid the bureaucracy of seeking official permission again. I talked about my concerns to the staff of AECC Carolina and straightaway they put me in touch with AECC Zaragoza. In contrast to my previous experience with the AECC, this time my access to the field was relatively easy. I say relatively easy because most of the Spaniards were away on holiday in August. Besides, according to the AECC's professionals, husbands or male partners are frequently less forthcoming than women when it comes to speaking about their emotions.

As I will explain in more detail in Chapter 3, a limitation of this study is that I could not represent the diversity of Spanish women because the access restrictions posed by the field. I began fieldwork with a clear mission to represent the diversity of experiences of Spanish women along the dimensions of class, age, ethnicity and religion. That is to say, I attempted to reach *Gitanas*, immigrant women, lesbians, bisexuals, differently-abled women, or those women who are typically "Other". To achieve this, I tried to use as many different ways and resources to access to them as possible. Yet, I regret that I could only reach working or middle class, heterosexual, white *paya* women - with the exception of two lesbians. Working with the AECC in Carolina and Zaragoza did not help me to incorporate difference as for unknown reasons there is a considerable homogeneity amongst its members in terms of race, ethnicity, and even social class.

1.3. The Spanish National Health System

Spain is a constitutional monarchy but has been governed by a democratic parliamentary system since 1978. Spain has a population of 45,283,259 (INE 2008) and is organized territorially into 17 ACs and two autonomous cities, Ceuta and Melilla, in the north of Africa (Figure 2). ACs are subdivided into 50 provinces. The Spanish Constitution (CE) grants ACs the right to self-governance. The significance of this for the health of Spaniards should not be underestimated. It means that NHS services operate independently *and* differently between ACs, and are politically accountable to the relevant AC, generating inequality in access to health care as I will discuss in what follows.

Figure 2 Map of Spain and its ACs



The Spanish Constitution guarantees the right to health protection and right to health care of all Spaniards and foreigners living in the Spanish territory regardless of their AC of residence (CE art. 43). Thus, all Spaniards and foreigners are entitled to receive free NHS treatment. Data from 2005 claim that the NHS covered 99, 5% of the population “including low-income inhabitants and immigrant adults and children” (Durán et al. 2006: xviii).

The NHS was launched by the social democratic party PSOE under the General Health Care Act of 1986 (*Ley General de Sanidad de 1986, LGS*). It was born out of a long history of development of social protection which goes back to the 19th century when the first “Code of Public Health” (*Código Sanitario*) was approved in 1822 (Ley 14/1986: 1). The NHS has four core principles (Ley 16, 2004 de 28 de mayo: 1): universal coverage; free at the point of delivery; responsibility to provide high quality integrated care for all; and publicly run in order “to guarantee the right to health of all Spaniards” (Álvarez González 2007: 10).

These four principles guided a long process of decentralization of the NHS which was completed in 2002. It was thought that decentralization would favour equity by giving autonomy to ACs with regard to planning, public health and health care (MSC

2006a: 17). However, decentralization has since been defined as an unfortunate source of problems in terms of efficacy, universality and equity (Álvarez González 2007; Tornos Más 2002; CAS MADRID 2008).

The hurdles of decentralization quickly became apparent, and soon after the process was completed, the “Law on Cohesion and Quality of the NHS” (*Ley de Cohesión y Calidad del NHS*) was passed in 2003 in an attempt to resolve these problems. Thus, the LCCNHS emerged as a tool to foster coordination and cooperation between ACs and the State. The aim of the LCCNHS was to guarantee equity in access “of all peoples living in the Spanish territory” regardless of AC of residence; provide quality services so all patients have optimal and appropriate care in the safest environment; and promote patients’ involvement in decision-making, planning and evaluating their health system (MSC 2006a: 19).

1.3.1. Organization of the NHS

The Spanish NHS is responsible for government policy regarding Spanish “general” health matters, legislation over the pharmaceutical industry (including pharmaceutical prescription and price regulation), and for international health matters (Durán et al. 2006) such as swine flu or tropical diseases. It is also responsible for coordinating the ACs with regard to health. ACs are responsible for legislating on public health and managing health resources.

At first glance, it seems that the ACs’ health policies remain similar in most aspects. Indeed, popularly there is a tendency of talking about the NHS as belonging to a single, symmetrical, unified system. But some important differences have emerged between ACs in recent years jeopardizing equality and quality of care (CASMAdrid 2010). These differences are particularly salient in the provision of breast cancer care.

A fundamental issue for Spanish breast cancer patients is that the foundations of the NHS lie on the “principle of solidarity” (MSC 2006a: 27). In other words, no breast cancer patient in Spain has to pay to get access to treatments and care which otherwise would be unaffordable for most families⁶. The Spanish NHS is characterized by its non-

⁶ The experience of Sugar, a middle class woman, helps give a rough estimation of how much breast cancer treatment cancer can cost. After a negative experience with the NHS, she decided to receive cancer treatment in the private sector. She spent 12 million pesetas (£48,000) during the first eight months of treatment alone. Sadly, Sugar had one recurrence after another and when I met her she had been receiving cancer treatment for the last seven years. When I asked her how she could afford to pay for the treatments for so many years, she told me that she had the help of her family. She also explained how she managed

contributory regime where the contribution of Spaniards is based on their economic capacity, but they receive health care depending on their needs. This last statement, however, is problematised by wider structural forces like gender, age, class, or ethnicity, and by political contexts like geographical location.

The core funding structure of the NHS relies on public (70%) and private (30%) resources. Public health financing comes directly from general taxation whereas private financing is mainly “out of pocket household expenditure” (Rodríguez et al.1998: 166). Although public health funding is the responsibility of each AC, the State dictates the rules to calculate taxation schemes and minimum expenditure on health services.

Another issue very relevant to breast cancer patients is that the drugs or medication provided during specialized care and oncology are free to patients. However, patients have to pay up to 60% of the total of most outpatient and primary care prescribed drugs and prostheses. Patients can apply for a reimbursement of the prosthesis (MSC 2006a).

1.3.2. Provision of Breast Cancer Services. The Strategy against Cancer of the National Health System.

Remarkable progress has been made in the fight against cancer in Spain in the last decade. As I already mentioned, the most spectacular progress is the increase in survival rates for many cancers previously thought incurable, including breast cancer. Some of the key factors in raising survival rates are free treatment, early diagnosis, improvements in cancer treatment and advances in surgery. In addition, Spain is one of the world three leaders in terms of quick adoption and uptake of innovative cancer drugs, which, according to the Karolinska Institute and Stockholm School of Economics’ report about cancer treatment in Europe, is what determines survival rates (Wilking and Jönsson 2005: 2).

In spite of these achievements, the Spanish NHS was confronted with the challenging task of coordinating ACs’ cancer control efforts as there is sound evidence that this makes a difference in mortality and morbidity outcomes. Moreover, the Spanish Federation of Oncology Societies (MSC 2006b: 55) drew attention to the fact that the ability to coordinate cancer control efforts also needed to address the fact that

to get clinical tests (blood analysis, scans, screenings, x-rays) in the NHS although she received the pharmacological treatment in the private hospital. The example of Sugar is an exceptional one and most of the Spanish families could not have afforded to pay for this themselves.

equity in oncology demands quality of care. With this goal in mind the Strategy Against Cancer of the NHS (ECSNS) was launched in 2006.

Achievements and Weaknesses in the Provision of Cancer Services

The ECSNS was born with the ambitious goal of coordinating efforts, research initiatives and cancer resources in Spain in order to guarantee the highest quality of cancer care for all citizens regardless their place of residence. Ultimately, the ECSNS-06 was developed to reduce cancer incidence and mortality and maximise quality of life and access to services. In other words, the ECSNS-06 was designed as a guideline to provide national standards of clinical practice and care for all the ACs. It provided up to date information and recommendations regarding best practices in the areas of: promotion and protection of health; early diagnosis; adults care; children care; quality of life; palliative care; research.

The ECSNS-06 was promoted and approved by the Ministry of Health and Social Policy. It was drafted and implemented through a partnership with ACs, scientific associations and renowned experts in the field of cancer. The Spanish Association against Cancer (AECC) played a crucial role in attracting attention to the need for an “overarching” guideline for all the hospitals and health centres working for the NHS. An update of this guideline was published in 2010 (ECSNS-10). The ECSNS-10 took into account both new research evidence and the results of the evaluation of the previous guideline. Many of the areas of concern in the new guideline were confirmed by my fieldwork. I shall return to this point at the end of this section as it is important to understand the empirical chapters. In what follows I will outline the main priority strategies of the ECSNS-06. For reasons of space and time I will focus on the areas relative to my research.

(1). *Health promotion and health protection.* In this area tremendous importance is placed on the importance of raising consciousness and educating about healthy behaviours associated with cancer prevention or to reduce risk. Emphasis is given to the dangers of smoking, obesity, alcohol intake, unhealthy eating, UV ray exposure and some professional chemicals. To achieve this, the NHS works with partner organization, corporations, NGOs, the AECC, schools and regional governments.

(2). *Early diagnosis and screening programs.* The main objective of screening is to reduce morbidity and mortality by diagnosing cancer. Early diagnosis increases patients

quality of life as usually requires less aggressive treatments. It also reduces NHS' expenditure. Spain has screening programs for breast and uterus cancer. Screening for colorectal cancer is still in its experimental phase. Here I will focus on breast cancer screening programs. The main objectives of this program are:

- Guarantee breast screening for women aged 50 to 65 years;
- Screening should be every two years;
- Ensure close and individualized follow up for women with antecedents and genetic test when appropriate;
- Achieve a minimum of 70% of women's screening participation;
- Inform women of what the screening programme is about and what a mammography is, its benefits and risks;
- Maximize the quality of the mammography units to reduce the possibility of false positives and minimizes radiation;
- Follow up cases to ensure that the confirmation of cancer diagnostic takes place and reduce waiting times to receive treatment;
- Create interdisciplinary units specialized on genetic counselling in all ACs;

Nowadays, all ACs have well-established universal and free screening programs. Navarra was the first AC to set up its program in 1990. Gradually all the ACs incorporated breast cancer screenings to their health services. In 2001, 11 years after the first screening program was set up in Spain, Ceuta, the forgotten region, was the last city to include breast cancer screenings to its health agenda, evidencing significant inequalities in the provision of breast cancer screening services among ACs.

Spanish women are routinely invited to participate every two years. The Department of Health of each AC is responsible for sending an invitation letter to women. Information from the health card (*tarjeta sanitaria*) is preferably used to identify eligible women. Based on EU and ECSNS broad recommendations, screening practices vary from AC to AC. For instance, Castilla La Mancha, Castilla y León, Ceuta, Valencia, Galicia and Navarra recommend mammography by age 45. The rest of ACs recommends mammography beginning at age 50. There are also two variations in criteria to stop screening by age 65 years or 69 years.

(3). *Adults Care*. This area is primarily concerned with the collaboration of different specialists in the therapeutic process in order to achieve the maximum therapeutic

efficacy. Therapeutic process includes both the phase of diagnosis and the phase of treatment (e.g. biopsy, chemotherapy, radiotherapy, hormone-therapy and surgery). The main goals in this area are that:

- All patients, regardless their place of residence, should be offered an urgent referral within 15 days of detecting any anomaly;
- All patients should be offered a therapeutic plan within a week of confirming definitive diagnosis;
- All patients should be treated by a multidisciplinary team;
- All patients who need chemotherapy should be treated within 2 weeks;
- All patients who need radiotherapy should be treated within 4 weeks;
- All patients who need surgery should be treated within 1 week;
- Determine what procedures should be realized in specialist units in to ensure the best outcomes.

(4). *Quality of life* is an important and emerging area. The combination of an increase of cancer rates and the growing population of cancer “survivors” makes that this area be fully embedded in the patient care pathway. According to the ECSNS, quality of life must include clinical, psychological and social care as well as rehabilitation. The main goals are:

- Assess the economic, psychological and social needs of cancer patients within the NHS from a gender approach;
- Develop tools and strategies to identify those patients who may need psychological care;
- Research the state of the provision of psychological care with the NHS;
- Research the long term effects of treatments;
- Promote the emotional engagement of all health professionals working with cancer patients;
- Improving health professional’s ability to communicate with patients;
- Provide psychological care to all patients and their families who need it;
- Provide social support to patients and their families. This include informing patients; about their rights and obligations, providing practical support to the re-insertion in the labour market, promoting support groups for cancer patients and their families. Increase rehabilitation resources for cancer patients, especial attention should be given to rehabilitation and/or prevention of arm lymphedema;

- Palliative care. The main goal of this area is to improve and expand supportive and palliative services for adults in phase terminal;
- Research: investing and promoting collaborative projects on biomedical research on cancer.

In order to support and reinforce the guidelines of the ECSNS, Castilla y León, AC of which Carolina is a province, launched its regional cancer plan or onco-guide. This cancer plan was particularly concerned with developing specific “guides” for the most common cancers in order to establish regional standards for cancer services and expand the provision of services. Despite these cancer plans being achievements in themselves, and despite enormous attempts being made to implement them, the ECSNS-10 acknowledged some structural inefficiencies and difficulties that hampered equity and quality of care across ACs and within ACs, especially in Carolina. I shall return to this issue in more detail in another connection in Chapter 6, but at this point I want to highlight some of the key barriers to the effective implementation of the ECSNS-06 and Castilla y León’s onco-guide, especially by means of examples from the field. I hope that these examples give the reader an insight of the multiple ways in which the provision of cancer services may affect women’s experiences of breast cancer.

In what follows I will describe the five key barriers to the effective implementation of the ECSNS-06 and Castilla y León’s onco-guide.

The first barrier mentioned by the ECSNS-10 is the asymmetrical distribution of resources across ACs. Two clear examples are the uneven allocation of oncology units and breast units across Spain. For instance, in 2001, only 143 of 779 hospitals had oncology units specialised in the care and treatment of cancer, and only 87 of these units had radiation oncologists (MSC 2005:161-162). This situation has worsened as a consequence of the endemic and alarming scarcity of *medical oncologists* and *radiation oncologists* in the country which is expected to deteriorate in the near future, seriously jeopardizing professional replacement. This situation is even more dramatic in some areas regarded as unattractive (e.g. “second class” hospitals, provincial cities or towns) as it is the case of Carolina.

The unequal distribution of breast cancer units is another area of concern for some organizations like the Spanish Federation of Breast Cancer (FECMA) or the AECC. Castilla y León’s onco-guide also recommends the need to create specific units for the

treatment of breast cancer (Junta de Castilla y León n.d.:52). A breast cancer unit plays an essential role in improving effectiveness in the quality of services (Martínez García et al. 2005). It is characterized by a “team approach” that coordinates specialized nurses, surgeons, gynaecologists, radiologists, oncologists, pathologists, and sometimes even psychologists and plastic surgeons. The main benefit of breast cancer units is that all the therapeutic options that a patient may need can be found in one location, without the need to move from one consultation to another, causing confusion and inconvenience to the patient (Taboada 2006). FECMA (2010) has been demanding for years that breast cancer units be evenly distributed across all ACs in order to ensure that all breast cancer patients benefit equally from the best possible diagnostic procedures, treatments and care. Although more research is needed, I presume that breast cancer units would be more successful in recognizing and treating women’s health concerns that I describe in Chapter 5 because of their holistic approach. However, despite the creation of effective breast cancer units being central to the implementation of the ECSNS and recommended by the onco-guide, Belén Merck (in Perancho 2008), reports that in Spain there are only “25 real breast units, the others are rather virtual”.

The second barrier is direct result of the first one. As a consequence of the shortage of health professionals and resources there are significant waiting lists to receive appropriate treatments causing unnecessary distress. Of course, these waiting lists are more acute in some geographical areas than in others. In some provinces such as Carolina, where I did my fieldwork, cancer patients do not have the facilities to receive *radiotherapy*. In order to receive their treatment essential to survival, they have to travel to the closest hospital equipped with a radiotherapy unit. Sometimes, the closest unit available is 350km away. Note that the technique of *selective lymph node biopsy* (SLNB), or minimally invasive armpit surgery, used to determine whether cancer cells are present requires a radiotherapy unit. I will return to this point in Chapter 6.

Third, the ECSNS-10 points out that there is a huge variability of cancer care practices within ACs, hospitals and health specialists. Two points of capital importance follow. First, quality of treatment depends on the geographical location and “infrastructure”, but also depends on the type of care received. And second, variability is exacerbated partly by the lack of clear referral pathways and also as a consequence of an unequal distribution of resources. And this is not less true in the province of Caroline despite its pretty carefully detailed cancer-guide. Indeed, in the absence of appropriate

referral pathways and unevenness of care among health professionals, my informants complained about receiving unequal treatment and care.

To illustrate this further, allow me to provide you with an example from the field. Corroborating the ECSNS-10 findings, I found that referrals and therefore the type of care provided, depended very much on the individual professional who attended women first. Habitually, GPs, health professionals working on screening programs or private gynaecologists were the first ones to examine or attend women and referred them to a specialist if the woman presented with the symptoms of cancer. Other times, the woman herself would find a lump and would seek help in the emergency department (*urgencias*). The problem arose because there was not a clear referral pathway which dictated which “cancer specialist” must examine the woman first. Oncologists, surgeons or gynaecologists can be all specialised on breast cancer and yet all of them have different approaches to cancer and cancer care. So for example, in the province of Zaragoza the women’s most striking perceptions were that if the patient was referred to an oncologist there was more chance to keep a part of their breast. However, if the patient was assigned to a surgeon the “unavoidable” representation of the outcome was a mastectomy. Oncologists were described as initially in favour of chemotherapy in order to shrink the tumour and try to save a part of the breast. Although surgeons did recommend chemotherapy too, they focused more on encouraging women to remove their cancerous breasts as soon as possible to avoid further risks. According to these women, the discourse of surgeons was: “the best way to solve the problem is to attack the root of it”.

In contrast, in Carolina women’s concerns were slightly different. Carolina had only one hospital which was relatively small and so was the cancer unit. In Carolina the “cancer specialist” who attends or evaluates a woman immediately after she had been referred could be a surgeon or a gynaecologist. Surprisingly, here women commented on the aesthetic outcomes of breast surgery if the patient was referred to the surgeon or to some of the gynaecologists who also performed breast surgery. In general, the perception was that surgeons were more skilled and “refined” to operate the breast. This meant that breast surgery was more likely to be more aesthetic than if gynaecologists carried out the surgery. Again, this example evidences the different outcomes depending of the specialist who assesses women first.

The forth barrier is related to the lack of coordination between the different care levels and health services involved in diagnosis, treatment and follow up. Lack of coordination can result in fragmented care, waiting times, distress and unnecessary morbidity.

Finally, the ECSNS-10 echoes a widespread concern with the limited resources allocated to psychological and social care as well as for rehabilitation. Note that Castilla y León's cancer-guide advises to provide psychological treatment all through the therapeutic process, including during the phase of diagnosis. Because of the inefficacy of the NHS in meeting all the patients and families psychological and social needs, the AECC has found itself in the role of provider of cancer care packages, under ethical and political pressure to cover all those areas that the NHS fails to provide. I will return to this point in the next section when I explain the role of the AECC in Spain.

As these examples illustrate, barriers to the implementation of the ECSNS and Carolina's cancer-guide are tangible and do affect the therapeutic process. This means that Spanish women do not always have equal access to the best treatments and care available. Consequently this affects considerably their morbidity and quality of life outcomes. All these factors will be linked to women's experiences of ALND (invasive armpit surgery) and sexuality, which are fully explored in Chapter 6.

1.4. The Location of the Study

In this section I pay brief but special attention to the AECC because it is the national centrepiece of the effort on cancer. First, it is Spain's leading non-profit organization (NPO) dedicated to biomedical research on cancer. Second, it has a pivotal role influencing policy making and raising awareness. Third (and very importantly for my informants and society in general), it plays an essential role in providing emotional, psychological and social care for cancer patients and their families that the NHS fails to provide. I will analyse the therapeutic role of the AECC and examine how it is experienced as a social support in Chapter 5. Also, the AECC deserves a special section in this thesis because it made this research possible. It helped me to contact women who were willing to talk about their experiences of breast cancer, and provided a "safe" space for women in which I could carry out interviews.

1.4.1. The Spanish Association against Cancer

The importance of the AECC is that it is a well known institution in Spain. Because of its political influential force, it is a reference for cancer patients, their families and health professionals.

Founded in 1953, today the AECC is the largest NPO working on cancer operating at a national level. It has 52 offices in each of the provinces and exists in more than 2000 localities providing a pretty good coverage of the Spanish territory. The AECC was the first institution which made cancer a public concern and recognized breast cancer as a major social issue. And it is important to emphasise that all services are provided to cancer patients free of charge.

Unlike the UK and the USA, which each have a rich array of support groups and national organizations, in Spain the AECC is the only NPO with resources to offer to cancer patients and their families, as well as to society in general. What it makes it unique from other cancer charities is that it works against cancer “in every possible way which is known” (AECC 2007c: 8). It is imperative to stress two points here. First, despite the fact that the politics of the AECC are deeply influenced by a biomedical model, it also envisages many of the challenges encountered in the fight against cancer and seeks to address them as comprehensively as possible. This means that while enormous efforts go to raising money and funding for clinical investigation, consciousness raising and screening campaigns, the AECC embraces the areas of emotional and practical support to cancer patients and their families. This vision reflects its guiding principles of:

- (1). Representing society: the AECC lobbies for legislative and policy changes that improve patients’ access to health care and quality of life and guarantee research funds devoted to cancer research and prevention.
- (2). Collaborating with national health services, scientific research centres and other institutions which work against cancer.
- (3). Promoting cancer patients’ role as active agents in decision-making processes as well as encouraging citizens’ associations. The AECC acknowledges the need to involve both patients and citizens in the quest for solutions against cancer.
- (4). Planning and implementing of strategies, programmes and services. For example, the AECC played a crucial role in drafting the Strategy against Cancer 2006 described earlier.

(5). Funding biomedical research projects.

This leads squarely to the second issue already mentioned in the previous section: the AECC is also the leading charity because it provides the psychological, emotional and social care that the NHS and the ECSNS fails to provide

The AECC has grown through support from people in society and public funding as well as from corporate partnership. It is substantially funded by the central government (25.59%). In 2006, besides receiving funds from different ministries, it received financial support from more than 300 regional and local public institutions.

Increasingly, there are more corporations eager to support the AECC by donating money or by launching “supportive products” (*productos solidarios*) or commercial marketing partnerships. Membership, lottery and fundraising events are also key sources of funding. It is worth noting that the number of members has duplicated in the last decade from 41,854 members in 1998 to 83,792 in 2006 (AECC 2007c: 77-81). The AECC believes that this increase is in part because of its projects are very visible through the media, educational campaigns and “marketing partnerships”, and in part because internet makes easier to become a member.

Not surprisingly, the AECC is one of the Spanish NGOs with more financial resources. It has a yearly budget of more than 44 million Euros⁷ that runs hundreds of projects on a variety of breast cancer issues on a national level. In addition, the AECC collaborates closely with other foundations, charities, national and international public institutions and research projects including the NHS, Europa Donna, International Union against Cancer or the Framework Convention Alliance.

Key projects that deserve mention are:

- Funding cancer research projects.
- Screening campaigns which are independent from the NHS but coordinated with it. In 2006, the AECC provided breast screening for a population of 269.517 women across Spain.
- Support groups on a variety of cancer issues such as give up smoking or grief and mourning.

⁷ <http://apadrino.com/las-ong-espanolas-con-mas-presupuesto/> 13 April 2011. Mirada en 30th Sept. 2011

- Organization of more than 869 conferences, seminars and workshops to inform and raise consciousness on healthy eating, healthy life style, skin cancer, gynaecological cancers and prostate cancer.
- Psychotherapy services. These can be provided in the form of individual psychological therapy to improve patients' well-being and facilitate communication between family members. or psychological group therapy. These services are increasingly on demand among Spaniards diagnosed with any type of cancer, especially given the failure of the NHS to provide emotional support. Note that the number of patients treated by AECC doubled from 11,132 in 2001 to 22,117 in 2006.
- The AECC also has a wonderful national and local support network specialised on breast cancer. The aim of these support networks is to provide a safe and supportive environment which will facilitate a sense of community as they share their thoughts, feelings, advice as well as listen to others in the same circumstances. I will return to this issue in Chapter 5. Besides, this project facilitates workshops relevant to breast cancer patients such as sexuality related issues and prevention and rehabilitation of *lymphedema* or arm swelling as a consequence of armpit surgery
- Provision of legal and practical services. For example, this service provides information and guidance on benefits, financial help for patients or employment rights. It also offers information and support to help patients find available prostheses and accessories.
- The AECC also creates opportunities for volunteering and training for patients and survivors. Indeed, a valuable service provided is "testimonial volunteers" (*voluntarios testimoniales*). A testimonial volunteer is a cancer survivor who shares their lived experiences and embodied expertise with newly diagnosed patients. Volunteers can provide support at the hospital, at the AECC itself, and sometimes at patients' homes when the patient or his/her family request so.
- Cancer homes and flats for those patients and their families that have to travel considerably to receive treatment. Actually, the AECC owns 21 cancer homes in the main cities in Spain.
- Psychotherapy and leisure activities for children with cancer
- Palliative care for dying patients. Domiciliary palliative care is one of the latest services incorporated into the AECC, aimed at addressing the needs of terminally ill

patients. This project, although very important in the AECC, is still in its early stages and does not have much coverage as a consequence of lack of funding.

- Social activities in which patients can meet other persons living under the same circumstances. These activities include outings, workshops or social fundraising events such as the money collection week (*cuestación*), selling Christmas lottery and the annual NPO street market (*mercadillo*). Many Spaniards contribute by donating unwanted items for sale and by buying in the market. Many volunteers and members often contribute by donating the handcraft artworks they have created in the workshops organized by the local AECC. On the basis of these services, patients choose what seems to be the most appropriate source of treatment for their condition.

Having enumerated the AECC's key political role in the war against cancer in Spain, it should not be surprising that it was declared to be a public utility by the Ministry of Health in 1970.

1.4.2. The AECC in Carolina

At the beginning of my fieldwork I travelled from the north to the south of Spain conducting individual interviews arranged through the internet. However, once I got official permission from the AECC I moved to one of its headquarters in North West Spain. I lived in Carolina, a provincial city, from February to June 2009. Given that Carolina is very much like a town where many of its residents know each other, and also know residents from nearby villages, names of places, people and some occupations or identifiable traits have been changed to guarantee confidentiality.

The AECC opened its doors in Carolina in the 1990s. *La Asociación*, as it was commonly called, was defined as a safe, welcoming, open and accessible space where cancer patients and their families could find opportunities for therapeutic activities and connect with other persons in the same circumstances. I will explore how the AECC is effectively, and affectingly, integrated into a sense of social support in Chapter 5.

La Asociación is totally manned by volunteers apart from Pedro, the coordinator, Noelia and Sandra, the psychologists, and a medical doctor, whom I never met, who works in the palliative care team with Sandra. It has 461 *socios* (members) whose donations are essential to its existence. Of these, 76 *socios* participate actively in the rich life of *la Asociación* as volunteers (e.g. fundraising, doing administrative jobs, acting as testimonial volunteers, etc.). Not all the members are Carolina residents,

indeed, many of them are from different villages and towns scattered across the province.

When I did my fieldwork *la Asociación* was situated in a second floor rented apartment in a very privileged part of Carolina, very close to the cathedral and with views of the river. A year or so later Pedro informed me that *la Asociación* moved its headquarters to an apartment which was more accessible to the public, in terms of distance (the new location is in the centre of Carolina) and accessibility for disabled or elderly members as it has a lift instead of stairs in the main entrance.

La Asociación had three rooms as well as a meeting area and a toilet. Noelia, the psychologist, had her office/practice in one of the rooms. The office of Pedro, the coordinator, was in another room. He shared his workplace with Sandra, the psychologist responsible for the palliative care project, who worked once a week. By definition, I am not very sure whether Pedro's workspace could be called an office. It was always full of activity, frequented by cancer patients, relatives, persons asking for information, *socios* and volunteers. Many times I was amazed at how he was able to get work done efficiently with so many of us around chatting loudly, laughing or asking him for information. Another of the rooms was set up as the president's office. *La Asociación* kindly offered me this space to conduct all the interviews. This proved an invaluable, comfortable and safe atmosphere for my informants who were familiar with *la Asociación*.

The fourth and biggest room was the common room. It was a multi-functional space where cancer patients and survivors could meet just for socializing, talking to others about their experiences, or sharing information. Free workshops and group therapy were facilitated in this room too. Workshops were lead by professionals, usually by psychologists, but also by health professionals from the Valdecorral Hospital with which *la Asociación* had a very good working relationship, as I will explain in Chapter 5. Workshops covered themes relevant for members, including how to stop smoking, breast cancer and sexuality, or how to deal with mourning and bereavement. Very often, the common room became a hectic place where *socios* organized logistical or social events. For example, the common room was used as a workshop where *socios* created handicraft accessorizes to be sold in the annual charity flea market (*mercadillo*) in June.

La Asociación is also a place where cancer patients and their relatives can find a space to meet others in similar situations, or just to be heard. I could observe the

invaluable role testimonial volunteers played to alleviate emotional distress and facilitate everyday coping strategies for newly diagnosed cancer patients. For example, by helping to resolve fears and taboos about colon cancer, and by teaching the practicalities as well as “embodied techniques” (see Mauss 1973) of the colostomy bag.

Apart from the traditional groups, *la Asociación* organizes other activities such as outings, conferences or fundraising activities. There are three big annual fundraising activities that have become a symbol of the AECC: *el mercadillo* (the flea market) and *la cuestación* (collection day), and the lottery week. I participated in these activities as much as I could. For example, I helped to sell lottery tickets at Carolina’s main hospital; I fundraised money on a bone-chillingly cold Sunday, and participated in the dancing marathon. When Pedro was extremely busy, and none of the volunteers were around, I helped with answering the telephone, taking messages or doing small administrative jobs which allowed him to concentrate on more important things. Participating in these activities was my humble way of paying off my “moral debt” to Pedro (see Mauss 1971), who made my fieldwork possible as I will explain in Chapter 3. It was also crucial for gaining trust within the hierarchy of knowledge and for gaining the status of insider among those who had already welcomed me.

In *la Asociación* I made good friends with whom I could enjoy the rich cultural life of Carolina. With Noelia the psychologist I had many interesting fragmented conversations between her consultations. Noelia had been working at AECC Carolina for over 13 years. She was well praised by all her patients and their relatives. Pedro the coordinator resolved all my doubts about *la Asociación*. With him I got to know better how the AECC worked. He supported my research from the beginning and made my stay in Carolina possible. Pedro arranged all the interviews and introduced me personally to all the informants and *socios*, and whoever happened to be at *la Asociación*. The atmosphere in *la Asociación* was friendly and warm. I found it very easy to speak with members, volunteers and relatives. Although Carolina is a very small provincial city, I could feel the need of persons to speak about their everyday lives, fears or pleasures, and how *la Asociación* fulfilled this need.

Despite the fact that I only spent five months there, many of my informants and the volunteers were very keen to share their free time with me. They asked Pedro for my telephone number to invite me for coffee, concerts, family outings or to celebrate the traditional *Fiestas* with them. Indeed, one fascinating writer I met on an eccentric

course on “Indian health” told me that I knew more people and that I was busier than she, who had lived in Carolina all her life.

1.5. Conclusion

In this chapter I began by noting that we need to look at women’s narratives within the context in which their experiences are located, as this provides a critical overview of “the processes and forces that conspire, whether through routine, ritual, or, as is more commonly these hard surfaces, to constrain agency” (Farmer 1996: 262). To do so, I presented a panoramic view of the situation of breast cancer in Spain. First, I discussed the prevalence of breast cancer in Spain, attempting to present a picture of who gets breast cancer in Spain. Yet, I suggest that systemic studies, reports and policy on breast cancer in Spain are problematic because they construct the typical breast cancer patient as a homogenous woman, one who is a middle class, heterosexual, white Spanish born *paya* woman. Thus, the importance of axes of difference such as age, ethnicity, social class, geographic location in the probabilities of developing breast cancer or differences in mortality and morbidity outcome are rarely questioned. Then I presented the characteristics of women who participated in this study. In the second section, I focussed on the Spanish NHS. To understand the significance of the NHS in women’s access to treatments and care, I briefly described some distinctive features of the NHS and its organization. Then I turned attention to the National Strategy against Cancer of the NHS (ECSNS). I explain how the ECSNS was designed to ensure the highest quality of cancer care for all citizens regardless their place of residence by providing national standards of clinical practice and care. Although the ECSNS is in itself an achievement warranting recognition of equity in the provision of provision cancer services, it still faces many problems associated with the decentralization and shortage of health professionals and resources. Finally, I introduced the AECC, both because it is Spain’s leading charity providing the psychological, emotional and social care that the NHS and the ECSNS fails to provide, and because this research will not have been possible without its support. It helped me to contact women who were willing to talk about their experiences of breast cancer, and provided a “safe” space for women in which I could carry out interviews.

Chapter 2

Theoretical Perspectives: The Production of Breast Cancer Knowledge

2.1. Introduction

Whilst there have been important publications about biomedical research on breast cancer, and more recently (since the early 1990s) from sociological and anthropological approaches, Thomas-MacLean (2004: 629) has noted that much of this research has some limitations.

One of the main limitations is that, repeatedly, women's voices have been excluded from consideration and investigation. Such invisibility is, in part, the reason that breast cancer has not been studied as a "whole" encompassing both women's experiences along with the analysis of other social forces like class, age or race. Rather, research has tended to focus on dominant themes fragmenting the experience of breast cancer into small dimensions, which although very rich and provocative, does not provide an understanding of the lives of women within the context of their experience of illness. For example, research has focused on themes which attract funding, like sexuality (see Fosket 2000), the impact of treatments in women's bodies (e.g. alopecia, nausea, identity), or in deconstructing the politics of breast cancer by attacking the sexist nature of breast cancer discourses⁸ (see Sedgwick 1994; Jain 2007), but with the subsequent risk of reproducing the ideological bias which reduces breast cancer patients to their breasts. In this sense, by privileging certain themes, albeit of considerable importance, the danger is that women's voices, and the impact of wider social and political circumstances which shape their experiences, remain unexamined.

Sue Wilkinson regrets the lack of a feminist politics of breast cancer. She contends that:

⁸ I understand by discourse not only "the formal treatment of a subject in speech and writing" but also the practices that discourse generate.

Such a politics would refuse to collude in the discourses and practices promoting silence, invisibility and concealment of breast cancer. Rather (...) such a politics would lay claim to women's experiences of breast cancer through a multiplicity of stories and images (Wilkinson 2001: 275)

In this thesis I intend to follow Wilkinson's (2000a; 2001) and Wilkinson and Kitzinger's (1993; 1994) advice to listen to women's narratives of resistance which are "above all, metaphors of a revolution" (Wilkinson 2001: 1275).

Although women's experiences of breast cancer were very different depending on the woman's context, in this thesis I argue that all the narratives told me the same story; that of how social forces and cultural constructs impacted and shaped their lived experiences. Social researchers have long argued that the experience of health and illness has been determined to a large extent by socio-economic forces, and beliefs, values and practices. These define, as well as institutionalize, what kind of resources are available, how many, who has access to what resources, and the quality of resources which are provided (Janzen 2002; Finkler 1994; Lantz and Booth 1998; Lewis 2000; Collie and Long 2005). My aim is to provide a contribution to the body of literature on breast cancer through an exploration of women's narratives of resistance as a "micropolitical tool" (Hunt 2000) or "manifesto" with which to theorize from lived experience, and which openly questions and denounces the authority of the social structure. Particularly, I aim at exploring breast cancer patients' and survivors' concerns regarding their health, their families and close relationships, and their prospects for the future. I am concerned not only with how women *experience* breast cancer but also how women *speak* and *feel* about it. In doing so, this thesis investigates the social processes, sometimes violent, which shape women's choices and access to health care, in order to influence those processes and improve the delivery of health services for breast cancer patients.

Returning to Potts's (2000a) advice of revisiting the main discourses and practices around breast cancer, this chapter aims to examine how discourses of breast cancer have been "created" by different bodies of knowledge. The following sections outline the conceptual framework upon which this thesis is based, providing references and reflection on the relevant literature. Given the rapid spread of literature dedicated to the topic it would be almost impossible to summarize all the important themes and findings.

Instead, I highlight what I consider to be the more important theoretical issues and themes so that the meanings and emphasis provided by the following empirical chapters are contextualized for the reader. I am very aware that I have given prominence to social research at the expense of biomedical literature. My justification for doing this is simply one of space, and that I have been concerned to look at the themes most relevant for this thesis. As we shall see, this thesis touches on three main areas of knowledge: biomedical discourses, social perspectives, and lay understandings of breast cancer. These three theoretical approaches provide a way of systematising and critically analysing the huge volume of literature on breast cancer, and are then revisited in the light of empirical findings.

In the second section of this chapter I examine biomedical discourses on breast cancer. As we shall see, using the case of Spain, which it is a tiny microcosm of international trends in breast cancer research (see Tagliaferri, Cohen and Tripathy 2002), the vast majority of research on breast cancer lies within the realm of biomedicine. In order to understand the hegemony of medical knowledge, and how it impinges on women's experiences, it is necessary to consider what the term "biomedicine" means and examine its *modus operandi* from an anthropological perspective.

The third section of this chapter reviews literature that highlights how the experience of breast cancer cannot be studied in "static, ahistorical and biological terms" (Mullings 2000: 33). Despite the fact that these works opened a new ground for theorizing and research, they fail to analyze how social forces combine and intersect in complex ways to influence women's experiences. My thesis contributes to the recent trend in the study of social inequality in breast cancer by investigating how the intersection of "axes of difference" (Yuval-Davis 2006 in Davis 2008: 68) such as age, gender and class shapes breast cancer patients' and survivors' access to resources (e.g. employment, healthcare, leisure, benefits or social support) and the quality of care received (Bickell 2002; Escolar Pujolar 2008: 19; Mo 1992; Mullings 2000).

The final section addresses the tensions between biomedical and feminist understandings of breast cancer by looking at research on personal narratives of the illness. Lay knowledge of breast cancer offers a fruitful lens through which to examine the illness, as reflecting cultural anxieties and assumptions about the female body (see Riessman 1993). Narratives have drawn attention to subjective ways of understanding

the experience of breast cancer from the point of view of the sufferer. This has resulted in critiques of the reductionist biomedical approach which involves objectivification of the patient and the commodification of breast reconstruction and mastectomy.

Often these narratives come in form of autobiography (Potts 2000b), and as Thomas Couser notes, generally these narratives are the voices of “white women of the middle and upper middle classes who have the literacy, leisure, and inclination to write their stories - and the contacts to get them published - no published narrative, to my knowledge, tells of a woman suffering in isolation, as many women must” (Couser 1997:38). Unlike the UK and the USA, where there has been an explosion of autobiographical accounts since the 1970s (e.g. Picardie 1998; Spence 1988; Jain 2007; Broom 2001; Picardie 1998; Lorde 1997), to my knowledge there are only two such books that have been published in Spain. They uphold Couser’s observation; one of the works is by Professor María Ángeles Durán (2003), and the other is an autobiography of Mariam Suárez (2000), barrister and daughter of former Spanish Prime Minister Adolfo Suárez. In this sense, my thesis is a contribution to the literature on narratives of breast cancer as it seeks to recuperate the voices of Spanish women from the silence. Yet, as I shall explain in Chapter 3, given the difficulties I faced in the field, I regret that one of the limitations of my study was that I could not voice the experiences of non-white, non-heterosexual, non-able bodied Spanish women.

2.2. Biomedical Understandings of Breast Cancer

A rich scientific literature has dominated the body of research on breast cancer. This wealth of academic scholarship includes disciplines as diverse as oncology, surgery, clinical psychology, nursing studies, pharmacology, epidemiology, gynaecology or sexology, to name but a few. Highly profiled international conferences, seminars, funding programmes, research teams, and prevention projects showcase scientific scholarship on breast cancer. This interest is not accidental and we need to look in detail at how biomedical studies come to understand it, if we are to comprehend contemporary preoccupations with breast cancer.

In what follows, I pay deliberate attention to the concept of “biomedicine” to frame this section. The notion of biomedicine provides a useful way into the analysis of breast cancer as a “manmade disease” (Eisenstein 2001); in anthropological terms, as an

illness. Again, this is not to say that biomedicine does not have a positive impact on health outcomes, but rather that its impact should be seen in cultural terms rather than in narrowly defined “biological terms”.

2.2.1. Cultures of Biomedicine

The term biomedicine is used to refer to modern medicine, scientific medicine or evidence-based medicine. As used in this thesis, biomedicine refers to medical treatments such as chemotherapy, hormone therapy or radiotherapy, as well as to health professionals’ practices and the medical establishment’s ideologies. Before I move forward, I want to stress that by this I do not mean that health professionals always subscribe personally to this view of health and illness, but rather that it forms a more or less conscious ideology.

Since the end of the eighteenth century, biomedicine has appropriated knowledge over the body and diseases (Foucault 1973) to the extent that biomedical wisdom is synonymous with rationality, objectivity and efficacy in curing. Other varieties of medical knowledge, including patients’ embodied experiences, are silenced or discredited as irrational. “Alternative” knowledge is accused of being based on emotions or beliefs, not on “scientific” facts (Davis-Floyd and St John 1998 in Sharp 2000: 297).

According to Stedman (1976 in Hahn 1995: 133), the central concern of biomedical knowledge has been “not persons, nor their bodies, but the diseases of bodies”. That is to say, the main focus is on the observable facts derived from a physiological dysfunction of the body (Cassell 1976 in Helman 1994: 107). As we advanced into the twentieth century, this emphasis became especially salient in the study of cancer. Everything that is not measurable or “microscopically” observable (Medina Doménech 1996: 21) is “consigned to the realm of unreason and falsity” (Samson 1995: 56). Biomedicine became the legal and moral authority to define what health is, what disease is, and which the best treatment options are (Davis-Floyd and Sargent 1997). More important, biomedicine rules what an optimal state of life is, or should be (Rose 2007: 6).

While there is no doubt that biomedicine has contributed to the improvement of quality of life, as well as to the understanding and cure of many diseases which were previously thought to be incurable, including breast cancer, social scientists and

personal narratives of breast cancer have highlighted some of the limitations of modern medicine.

Now that we have a better idea of the “culture of biomedicine”, I will briefly present five main key criticisms of why biomedicine focuses on some issues, neglecting others. These criticisms are useful to understand how breast cancer patients deal with and navigate through the world of biomedicine presented in the empirical chapters.

The first critique is that biomedicine fails to accept the idea that medicine is not only a social construct, a culture, but that the construction is both sanctioned and perpetuated by biomedicine itself (Foucault 1973). As I mentioned, biomedical knowledge dictates which behaviours, suffering, emotions, pain or illnesses are healthy, legitimate or appropriate to be displayed. Consequently, it also rules which ones are deviant. It has been noted widely that biomedical classifications are based on cultural beliefs and norms of society as much as objectively defined facts (see López 1998; Rapp 1993). For example, anthropologists have questioned how the “medicalization of cultur(al beliefs)” (DiGiacomo 1999) ends up reproducing inequalities in access to, and delivery of, health care on the basis of class, race or gender (Standing 1997; Doyal 2002; Walter 1995; Wilkinson and Kitzinger 1993; 1994).

Medicalization of gendered cultural beliefs is perhaps most apparent in the literature dealing with women’s mental health. An example which is relevant for my argument in Chapter 4 is the case of hysteria, hypochondria, or endometriosis. These illnesses were understood as a disease of female reproductive organs. “The womb” (Greer 1999) was thought to be the cause of diseases of the nerves and of the imagination. In Joseph Roulin’s view (in Foucault 2001: 131), “women invent, exaggerate, and repeat all the various absurdities of which a disordered imagination is capable”. For decades, if not centuries, women’s complains were ignored, minimized or disregarded as all being in the woman’s head. Endometriosis, for example, was perceived as an invention of the hysterical woman well into the twentieth century. Today endometriosis has finally been recognized as “an illness of the body” however, it still bears the label of a psychological disorder (Shohat 1998: 241-246).

Another critique central to this thesis draws attention to the reductionism of biomedicine. By focusing only on the observable facts it delegitimizes many forms of suffering which cannot be understood, or are difficult to grasp, by biomedical methods. Some examples of suffering which escape biomedical understanding are chronic pain

(Brodwin 1992; Jackson 1992; Bendelow and Williams 1995), interpersonal experiences of trauma, suffering (see Lawrence 2000; Henry 1999), and disembodiment (see French 2001; Young 1990).

Pool and Geissler (2005: 77) argue that biomedicine is “materialist” in the sense that it understands disease as something physiological which can be observable and measurable. This materialism hides a Cartesian worldview grounded on the idea that body and mind are two mutually exclusive categories. Thus, it aims exclusively at curing the body-machine. This uncovers not only a fragmentation of the experience of illness, but also fuels emotional minimalism, antihumanitarianism (Spence 1988; Sered and Tabory 1999; Good 1994), “molecularization” (Rose 2007), and “ultimately allows for the commodification of the body and its parts” (Sharp 2000: 290). In the context of breast cancer, “mechanistic” understandings of disease may well be discordant with patients’ (dis)embodied experiences. For instance, as I will explore later in this chapter, contested meanings and knowledges of mastectomy lie at the heart of the Cartesian body and mind dualism. Whereas biomedicine sees the breast as an object which can be changeable (Noorzay 1990) or improved with breast reconstruction or breast prosthesis, many women appreciate their breast as a site of lived experience (Csordas 1990, 1993; 1994; Freund 1990), or a bodily extension of the (feminine) self (French 2001) which can not be restored (Young 1990; Hallowel 2000).

Another related criticism is that biomedicine fails to accept the idea that many diseases are profoundly social. Anthropology has been particularly effective in illustrating how diseases are both physiologically and socially produced. They are the product of larger historical and structural forces like class or gender, rather than product of each individual’s psychology and physiology (Bourgois 2004; Baer, Singer and Susser 1997; Castro and Singer 2004). Indeed, in the next section I will look more closely at how the intersection of structural forces, or axes of difference, affects people’s experiences of breast cancer.

Despite these criticisms, biomedical knowledge dominates understandings about health and illness. Indeed, as Rose (2007) notes, biomedicine has the ultimate power to rule “life itself” as my thesis, and the current state of discourses about breast cancer in Spain and in the Anglo-Saxon world, illustrate. In this thesis, I am interested in how biomedicine determines what health and illness are based on cultural knowledges about the (female) body, the ill person, and women’s expected behaviour.

2.2.2. Classifying and Defining Breast Cancer

A fundamental question to the production of biomedical knowledge concerns the causes of breast cancer. Central to biomedical discourses is the almost obsessive emphasis on framing its etymology, its symptoms, and its treatments. This notion helps us to understand why those ailments which are not quantifiable are disregarded as being in the realm of the “imagination”. The biomedical definition of breast cancer explains it as a malignant tumour which originates in the mammary glands. It is characterized by the abnormal division and growth of cells. Although it is very rare, comprising 1% of breast cancer diagnoses, men can also develop breast cancer (AECC 2008).

There are two common types of breast cancer depending on its location: *Lobular cancer* means that cancer started in the *lobes of the breast* where milk is produced. *Ductal cancer* is when cancer cells develop in the *ducts of the breast* which connect the lobes and conduct milk to the nipples (Eguino Villegas, Garcia Alvarez and Yelamos Agua 2007: 9). There are other types of cancer which are less frequent like, for example, *tubular cancer* which is characterized by the tubular form of its cells, or *medullar cancer* characterized by the bigger size of its malignant cells and because it contains white cells too (Cancer Research UK 2009).

Breast cancer is also classified into two categories depending on the stage of its growth. Cancer can be *in situ* or *invasive*. *In situ* means that cells have not spread into the surrounding breast tissue, lymph nodes, healthy organs, or bloodstream. It is also called early stage or non-invasive cancer. It is curable, but if not treated on time it may develop into an invasive cancer. Invasive cancer means that the malignant cells have spread into the surrounding tissue making its control and treatment more difficult. If cancer cells have entered the lymph nodes or the bloodstream it becomes a metastasis, as it is impossible to stop the spread of cells to elsewhere in the body. Metastatic cancer cannot be cured (US National Cancer Institute 2009).

There is no agreement on what causes breast cancer. In what follows I will describe briefly some of the mainstream discourses on what causes the disease: age, genetic factors, hormonal factors and lifestyle.

(1). *Age*: the risk of developing breast cancer increases with age. Macmillan Cancer Support (2008) writes that around 80% of all breast cancers occur in women aged 50 or over. That is the main reason why all the ACs in Spain provide free screening for all women over the age of 50 (see Chapter 1).

(2). *Genetic factors*: despite the considerable media coverage, the likelihood of getting breast cancer as a consequence of a genetic predisposition is very small, at between 5–10% of breast cancers. Although carrying the BRCA1 and BRCA2 genes increases one's chances of developing breast cancer to 50%, (Kelsey et al 1996 in Lynn and Ward 2002: 49) it is not a death sentence.

(3). *Lifestyle factors* such as alcohol intake, smoking, lack of exercise, or a diet rich in fat are thought to be, irresponsible habits which increase risks of developing breast cancer (AECC 2008c).

(4). *Hormonal factors*: estrogens and other hormones fuel the growth and proliferation of mammary cells. By exposing the mammary cells to these hormones during a lifetime, the risk of developing breast cancer increases since the greater the number of cells divisions, the more likely it is that one will result in a cancer-provoking mutation. During menstruation, the female body is exposed to increased levels of these hormones, so the more periods a woman experiences, the higher her risk of developing cancer. These are some of these experiences, or hormone risk factors, frequently listed as being the cause of cancer: early menarche (or menstruation at an early age), late menopause, nulliparity (not having had biological children), having children late in life (after the age of 30), the number of children, and history of lactation (AECC 2007b).

The magnitude of the authority of biomedicine to create knowledge and to sanction alternative discourses is manifest in the domination of “the rhetoric of risk, control and culpability” (Yadlon 1997) around breast cancer (see Wilkinson and Kitzinger 2000; Wilkinson 2001). It is interesting to note that most of the literature on breast cancer edited by the AECC diminishes, or undervalues, the risks of taking hormone replacement therapy (HRT) or the contraceptive pill, whereas these factors appear in the front page of almost any British charity website on breast cancer. Another hormone risk factor which is completely silenced in the mainstream Spanish literature, and marginalized by a good part of the British and American's decision-makers, is the impact of environmental pollution in disrupting endocrines (Valls-Llobet 2006b; Castleman 1994; Fishman 2000; Burton 2005).

My thesis is interested in how this discourse masks huge inequalities not only in incidence, who gets more breast cancer, but on the structural causes and consequences of it, why, and what the fortunes of women who suffer it are (Broom 2000).

2.2.3. The Monopoly of Biomedical Discourses in Research on Breast Cancer in Spain

In Spain, as in the Anglo-American world, biomedical knowledge historically has, and still retains, monopoly on cancer research, so receives most funding for it (see Thió 2008). It is worth pointing out that although biomedical knowledge is still predominant in the West, disciplines like medical sociology, medical anthropology, psycho-oncology, oncology nursing, social psychology, and social epidemiology are also well established disciplines in countries such as the United Kingdom, the United States or Canada. In these countries, knowledge produced by these disciplines has real implications for a variety of settings like policy making, citizen advocacy, medical academic research, or academic teaching, whereas in Spain, these disciplines struggle to produce and insert their knowledge into the heat of political and academic debate (Borrell et al. 2004a). Thus, the belief in Spain that social research has little or no value on the arena of health research contributes to explain the lack of funding allocated for social research on health, and, I feel, also accounts for my struggle to gain access to the field, as I will illustrate in Chapter 3.

To give the reader an idea of the weight of biomedical research on breast cancer in Spain, I used *Dialnet Database*, an online gateway whose goal is to be a major site for the circulation of Spanish scientific research, to identify published work on the issue. Key words chosen were “breast cancer”, “breast cancer and anthropology”, “breast cancer and sociology” and “breast cancer and psychology”. A list of 499 items was obtained from the key words “breast cancer”. Virtually none purported to use anthropological, sociological or feminist concepts. Only 4 items were obtained from the key words “breast cancer and psychology” and 7 with the words “breast cancer and psycho-oncology”.

For the sake of clarity, biomedical research on breast cancer in Spain can be broadly classified into three areas: clinical research, psycho-oncology and research on the impact of breast cancer on women’s body image.

Clinical research emphasizes the biological dimensions of breast cancer. It focuses on the development of new therapies (e.g. Estévez and Luch 2007; Grupo SOLTI⁹;

⁹ With regard to drugs improvement, SOLTI (The Spanish Group for the Study, Treatment and other Experimental Strategies in Solid Tumours) is the leading research body on medical treatments procedures, strategies and clinical trials with an extensive research published national and internationally. A full description of SOLTI’s research can be found at: <http://www.gruposolti.org/publicaciones.asp>

López et al. 2005; Rodríguez Sánchez 2005; San Román et al. 2007; Robles 2006; Torres Sánchez 2006; Gallegos Hernández 2003), prevention (e.g. Zamora Ardoy et al. 2004; Martín Moreno et al. 1994; Pollán Santamaria 2007; Fernández et al. 2006), the risks of oncogens on breast cancer (e.g. Vioque et al. 1993; López-Abente et al. 2000, Griado Álvarez et al. 2003; Cáceres Zurita et al. 2007), and epidemiology.

The second main approach to breast cancer in Spain is psycho-oncology which has carved a separate domain for itself within the study of oncology in recent years. Even though it is a branch of psychology, its roots lie deep with biomedical sciences. Given the importance attached to biomedical knowledge, it should not be surprising that the prevalence of biomedical approaches and medical jargon (e.g. coping competences, adaptation or adjustment) which present a sense of rationality and legitimacy (see Fabrega 1993) and which often focuses “on the machine-like nature of the body” (Samson 1999: 10). For example, many studies have employed variables associated with cancer adjustment (Cruzado et al. 2005; Barraza 2004) with the idea of developing better psychological treatments. Research indicates that adjustment to cancer improves survival rates and quality of life (Sánchez et al. 2005: 22; Die-Trill 2007). Perception of control, auto-efficacy, personal competence and social support are deemed to be key variables for an effective adjustment strategy (Manos et al. 2005).

Another tradition within psycho-oncology research aims to examine the links between women’s personality and health. The theoretical interest is usually based in those approaches which suggest that either personality Type C causes cancer or, that personality determines the adjustment to cancer but that it is not a premorbid trait (Martínez Lozano and Martínez Zaragoza 2003). Breast cancer patients who present Type C personality are described as able to control their emotions, especially negative emotions like anger or anxiety. They are cooperative and prone to self-sacrifice to avoid tensions with people in their social environment (Ruíz et al. 1998: 120). Martínez Lozano and Martínez Zaragoza (2003: 118) note that:

Women diagnosed with cancer seem to develop (...) a tendency towards deepening their traditional roles, evident in a more submissive way of relating to others.

The authors' portrayal of personality Type C fits well with the portrait of the Victorian breast cancer patients put forward by DeMoulin (1989: 612 in Thorne and Murray 2000: 146).

Relinquish all watching, all resistance, all inference, and sadly resolute to be wholly resigned.

This description of cancer patients with type C personality is, of course, not exclusive to breast cancer patients but is seen throughout literature on female psychology (see for instance Cardenal Hernáez 2003). Essentially, (the feminine) woman is *still* described as selfless, a caregiver, flexible, tolerant and affable. My thesis reveals how this social imagery of women's personalities have percolated out from academic discourse and, as it will be shown, has direct implications on how health professionals and family expect women to behave.

The majority of these works are quantitative and attach too much value to women's individual characteristics. More specifically, they tend to fail to take into account how women's (mal)adaptive behaviour is enabled or constrained by the social structure. Some Spanish feminist scientists have cautioned against the perils of this biological determinism. They argue that while such explanations may be useful in understanding a few specific traits of women's psychology, it cannot provide a theory to explain the cause of breast cancer. Further, they contend that such an approach is gender and class-blind because it fails to take into account cultural beliefs, social norms, or other socio-political factors that may influence women's behaviour. Additionally, it legitimizes women's "pathological" psychology as something biologically and innately given. According to Carme Valls Llobet (2003: 165), the medicalization of women's psychological profile "conceals socio-cultural constraints that shape women's personalities".

Echoing international trends (see Wilkinson and Kitzinger 1993; 1994; Saywell, Beattie and Henderson 2000), the final body of literature I present here focuses on the implications of mastectomy in women's sexuality. The dominant discourse is based on the assumption that the worst thing about being diagnosed with breast cancer is the trauma of mastectomy which "devastates woman's feelings of attractiveness and sexual desire" (Schover 1991). If traditionally women's sexuality has been seen as

synonymous with their body image, and breast loss leads to poor body image and self-esteem, the link seems inevitable (Manos et al. 2005).

Words like “depression” (Bartmann and Roberto 1996), “disfigurement” (Harcourt and Frith 2008), “reluctance to look at oneself naked, feeling less sexually attractive” (Fobair et al 2006), “sexual dysfunctions”, and “failed relationships” pervade both the Spanish and Anglo-America literature on breast cancer. In a similar fashion to the UK and USA, interest in this subfield has grown steadily in the past decades giving rise to many “Breast Cancer Handbooks”, seminars, conferences, and “lucrative pink products” (see *Think Before You Pink*; Klawiter 2000: 71-74; Fosket 2000; Baralt 2006; Jain 2007).

As a result, popular programs like *Look Good Feel Better* in the United States, or *Anímate al Cambio* in Spain (Obra Social Fundación “la Caixa” 2005) are aimed at restoring women’s femininity, and hence women’s sexuality. An important part of the work carried out by many charities and specialists working with cancer patients is to provide beauty tips for those suffering hair loss, dehydrated skin, fragile nails, breast prostheses and breast reconstruction. They warn women of the side effects of abrupt menopause provoked by cancer treatment, providing tips to fight it with healthy diet, exercise, lubricants or even “Victorian resignation” if they are too old to enjoy sexuality (Thorne and Murray 2000: 143-146). In this thesis I propose that sexuality be recuperated from the dominant biomedical discourses and social imaginary (Potts 2000a), in an effort to redefine theories of women’s sexuality and breast cancer from (dis)embodied experiences.

It is only fair to conclude this section acknowledging that in spite of the dominance of biomedical research on breast cancer in Spain, I am aware that there is an emerging literature in the fields of anthropology, sociology, health, and gender which could vastly contribute to my understanding of the social and cultural contexts in which the lives of breast cancer patients are framed. Knowing this is especially frustrating since I had many difficulties accessing published materials in Spanish. A large number of these publications cannot be accessed online. Worse, these works are disseminated across the Spanish geography, making its access beyond my financial possibilities. Furthermore, there is an issue of inclusion and citation here, that is, the importance of making more visible the work of Spanish academics about Spanish realities. To neglect their work is to do a disservice to them and to academic knowledge, including to this thesis.

2.3. Social Understandings of Breast Cancer

As we have seen, the emphasis on biomedical explanations of cancer causation, prevention, and treatments entails that some other crucial factors in the breast cancer *process* have been almost entirely ignored within the massive literature devoted to it. This is especially true in the Spanish context as the scarcity of social research demonstrates.

In this respect, social scientists have called attention to the need for developing a consciousness of health inequalities in “developed countries” within national health care systems (Navarro 2006; Sered and Fernandopulle 2005; Wilkinson 1996). They argue that the biomedical establishment tends to put the blame on individuals as responsible for their illness (Medina Doménech 1996; Yadlon 1997; Sherwin 1996), rather than looking at the underlying structural causes of personal choices and behaviours. Observing this tendency, Nancy Scheper-Hughes and Margaret Lock (1987: 10) noted that there is a “a missed identification between the individual and the social bodies, and a tendency to transform the social into the biological”.

In order to understand why some women do not comply with treatments, have low level of screening participation, or present more advanced stages of breast cancer at diagnosis, for instance, “one needs to look at their illegitimate position in the social sphere” (Fassin 2004: 207-208). This requires fine-tuning our glasses in order to visibilize the hierarchies which create health inequality in breast cancer. Structural violence and the inverse care law (Titmuss 1968 in Hart 1971), are two interrelated concepts that can therefore help us to examine how social forces that have been taken for granted, like gender, class or age, intersect to shape Spanish women’s experiences of breast cancer.

2.3.1. Unhealthy Breast Cancer: Breast Cancer and Social Inequalities

Bywaters and McLeod (1996: 3) note in the introduction to their book *Working for Equality in Health*, that “there is a relationship between social inequalities and health inequalities”.

The concept of structural violence is quite frequently applied to situations of conflict (Lawrence 2000), “third world” countries (Scheper-Hughes 2000), or in analysing the problems of marginal communities in the West, like immigrants in France

(Fassin 2004) or drug addicts in San Francisco (Bourgois 2004). However, it is also a very useful concept to explain health inequalities in breast cancer in Spain.

Structural violence refers to social forces deeply entrenched in the social structure that (re)produce situations of marginalization, oppression or domination of certain vulnerable groups. Some examples of such social forces are sexism, classism, racism, able-bodyism or ageism (Farmer 1996;1999). They are also defined as “axes of difference” (Yuval-Davis 2006 in Davis 2008: 68) as discrimination is based on the Otherness of the oppressed group, for example, old woman, non-*Paya*, disabled woman, or lower class woman.

Similar to the dramatic exclusion from the health care system experienced by immigrants in France (Fassin 2004), homeless women in the UK present a clear case of structural violence on the basis of class, which affects their prognosis when suffering breast cancer. The UK is a rich country, as its NHS defined as one of the “world’s largest publicly funded health service. It is also one of the most efficient, most egalitarian and most comprehensive” (NHS 2009). However, homeless women do not have access to all the care that they are entitled to by law just because they do not have a registered address, which ironically is the only prerequisite needed to receive care. In addition, the principle of equality is infringed routinely as homeless women are invisible to the prevention programmes. Again, because women are not registered with a GP (General Practitioner) (NHS 2010) they do not receive the letter of invitation to take part in screening programs. Thus, it is more likely that homeless women present more advanced stages of cancer when diagnosed which in turn are more unlikely to be curable.

The decentralization of the Spanish NHS provides another example of structural violence in this context. Decentralization, far from improving health for all, increases inequalities in access to health care (see CASMadrid 2010). As we saw in Chapter 1, the NHS is managed separately and differently by each AC. This is the cause of an asymmetrical distribution of resources between ACs. The more attractive and richer ACs have more medical resources like, for example, specialized breast cancer units, oncology units or radiotherapy facilities. During fieldwork I found that the implications of these policies can be sensed by breast cancer patients in many different ways. For instance, patients from poorer ACs had to wait longer periods in order to receive adequate treatment which increased the likelihood that the cancer would progress,

making its treatment and cure more difficult. Another example was the lack of facilities equipped to provide radiotherapy or SLNB. Patients who need radiotherapy had to travel on a daily basis to the closest hospital provided with an appropriate unit. If they were *privilegiadas*, the closest service available *no estaba muy lejos* (was not too far). But if they were not so fortunate, some women would have to travel up to 600km everyday for a month, and although the transportation was financed by the NHS, it deprived women of lots of energy and time to rest.

Qadeer and Visvanathan (2004: 145) argue that when structural violence in the health system or social care system affects for the majority of population (e.g. not young, non-white, non-able-bodied, non-upper class, not men) they must then be considered to be “unhealthy”. This phenomenon of “health Apartheid” or “blindness of policies” (Fassin 2004: 211) is what Hart (1971) termed “the inverse care law”. By definition, health care provision should be based on the sole criterion of necessity, yet in Hart’s view the best health care available tends to not to be for those who need it most, who are usually the most deprived, but for the better-off. Hart wrote:

The availability of good medical care tends to vary inversely with the need for it in the population served. This operates more completely where medical care is most exposed to market forces, and less so where such exposure is reduced (Hart 1971).

This chilling statement was supported by Titmuss’ extensive experience of the British social care system:

We have learnt from 15 years' experience of the Health Service that the higher income groups know *how to make better use of the service*; they tend to receive more specialist attention; occupy more of the beds in better-equipped and staffed hospitals; receive more elective surgery; have better maternal care; and are more likely to get psychiatric help and psychotherapy than low-income groups - particularly the unskilled (Titmuss 1968 in Hart 1971, emphasis added).

To borrow Fassin’s words (2004: 210), these examples “illustrate how one can have an excellent health care system, yet very poor results regarding the health of certain

groups”. This in turn supports Wilkinson’s theory that “social, rather than material, factors are now the limiting component in the quality of life in developed societies” (Wilkinson 1996: 1), an issue that my thesis aims to investigate among breast cancer patients in Spain.

Although there are many social structural factors which determine the conditions of women living with breast cancer, in what follows I will briefly look at the three main forces that have emerged from my empirical findings. These are gender, class and age.

2.3.2. Gender and Breast Cancer

The notion of gender has enormous importance in my research as I already showed in this chapter. Gendered ideas about women’s bodies, women’s sexuality and women’s behaviour shape biomedical practices, and, therefore, play an important role in creating health inequalities. However, biomedicine alone does not create inequalities in health. It is society, women’s families, and women themselves who bear and reproduce inequality.

Cecil Helman (1994: 162-163) noted that gender roles “may , like other cultural beliefs and behaviours, be either protective of health or pathogenic, depending on the context”. Several aspects of female gender culture can be said to contribute to breast cancer patients’ ill-health. The clearest example of the pathogenic nature of contemporary Spanish female gender constructions is manifested in the conflict between the role of sick patient and the role of the mother or wife.

This is not the place for a detailed examination of the sick role, but its understanding is essential if we are to comprehend women’s experiences of breast cancer. The sick role was coined by Parsons in 1951. He argued that the sick role is not only a factual biological condition; it is a social role which legitimates the right of the individual to withdraw “from adult responsibilities and as a basis for eligibility for care by others” (Fox 1968: 90-96 in Helman 1994: 110). However, in order for the person to be socially accepted as ill, (s)he has the moral responsibility of doing everything possible to recover their health: from seeking health to compliance with treatments and convalescence.

Studies on women’s health have challenged the gender-blind nature of Parson’s sick role theory noting that for many women the right to be sick is almost irreconcilable with the role of mother or wife. For example, oncologist Joaquina Lozano found in her

everyday work with cancer patients that there is a gendered difference between male and female cancer patients' attitudes toward treatment compliance and tolerance (Martínez Lozano and Martínez Zaragoza 2003:122). Although she argues that women are more submissive than men, she noted that recovery and compliance were paradoxically more difficult among female patients. By listening to her patients, she found that women tended to carry on doing the same tasks as they did when they were healthy, whereas most of men did not, sometimes compromising their recovery. In fact, in comparison to men, women found more difficult, if not impossible, to "enjoy" the sick role which excused them from their "normal" roles as mother, wives and housewives (see also Durán 2003).

Lozano observed that most women did not receive any help from their husbands with the housework, or care for children or the elderly. As Lozano put it: "they cannot rest properly, nor are they reminded to take medicines" (2003:122). As food still remains women's domain, she argues that it is unlikely that women receive a healthy balanced diet (so important in the Spanish cultural imagery of health) when they are on treatment. She explained: "when a woman is so tired that she cannot even move, you cannot ask her to cook soup or go buying fresh fish" (2003:122).

Similarly, in a key lecture at the international summer course on *Health and Gender* at the University Complutense of Madrid in 2007, Sánchez López said that even in the face of illness, (Spanish) women are still socialized to leave the house ready and clean for the family:

So by the time women enter the emergency room they have left everything ready and even cooked *la tortilla* for the family.

Research on women's health has shown that women perceive themselves as the cornerstone responsible for keeping the family healthy (Jackson 1997: 331). Women commonly express "their responsibility to protect others from their own suffering, hiding or minimizing their own pain and anxiety" (Wilkinson 2000a: 232) to the extent of prioritizing the well-being of their families over their own (Hockey 1997: 285; Anllo 2000).

The diagnosis of a life-threatening disease like breast cancer also confronts women with the dreadful possibility of death (Targ and Levine 2007; Kohlman 2006a, 2006b;

Lerner 2000; Davies 2002). One consistent finding across cultures is that from the beginning, the uncertainty about their future causes tremendous distress, terror and sadness to women. They worry about their own life, but also about the prospect of their children and partners. Disclosing news is problematic for many women. Who tells the news to whom and when is considered the most appropriate moment puts women in a quandary as they do not want to upset or worry their family. For some women, undergoing prophylactic surgery (Hallowell 1998, 1999, 2000) or genetic testing (Foster et al. 2002; Agincourt-Canning 2006) are the only options available to control the risk of cancer so that they can fulfil their moral duty as mothers or wives by protecting family members from suffering their illness and death.

The antagonist relationship between the role of mother-wife and the sick role is evident in the following extracts from a British and an Asian American woman:

We become very good at behaving ourselves, especially as women - we're very good at hiding what we feel and just putting on a brave face for everybody else (Wilkinson 2001: 271).

The Oriental way of thinking [is] placing the role of mother above the role of woman. [This] plays a big role in their attitude. The primary concern is to survive for the children, not be a beautiful woman for their husband (Ashing et al. 2003: 42).

As shown, gender roles may be pathogenic in the sense that they constrain women's convalescence and well-being while making that of others possible. Ill women are not only overburdened with the emotional work of concealing their own suffering and the signs of their illness to minimize others' anxieties (Broom 2001), but they engage in physical household labor which may delay or jeopardize their recovery. Feminists have long argued that health professionals and family should be aware of these gender dynamics and the difficulties they pose for women to seek help and to rest.

In a fascinating study which again challenges the gender-blindness of Parsons' sick role theory, Gray et al. (2001: 244-245) found that women's feelings and attitudes towards their role(s) were ambivalent. On the one hand, women resisted the passive role of patient: feelings of uselessness were used to describe the sick role, and women

admitted that they concealed or minimized the signs of their illness because they did not feel comfortable with their role as patients, especially because it transgressed their gender roles on a physical, emotional and moral level. On the other hand, women complained that once they “appeared quite well again” they were expected to resume their usual activities (Crouch and McKenzie 2000: 209-210), including sexual ones (Meyerowitz et al. 1999), problematising biomedical and social definitions of health. Besides, it is important to draw attention to the fact that looking good is not always synonymous with feeling well. Several months after the surgery, many women report “various physical discomforts *other* than painful intercourse” (Takahashi and Kai 2005: 1284) as for example feeling very tired, arm swelling, pain in the radiated area or fear of recurrence¹⁰.

These findings are not unique. A recent study by Sulik (2007: 860) found that while breast cancer patients care for others’ well-being, they do acknowledge the need to take care of themselves too. “The balancing act” is a central concept in understanding how women manage the conflicting relationship between the sick role and the role of mother-wife. It reconciles the moral duty of helping others with “the transgression of gender norms” such as receiving or asking for help. Yet, Sulik (2007: 867) argues that the politics of the balancing act are not completely liberatory but gendered in themselves. This leads to a conflicting situation where women feel anxious and guilty about saying *no* or when they ask for help for certain “minor” tasks such as preparing meals, taking the children to extra-curricular activities, or doing the washing up. In an attempt to lessen the transgression of gender-specific-rules, women “hold out the promise of future reciprocity or seek others’ approval for the transgression” (Sulik 2007: 867).

It is worth highlighting that nowadays, many cancer programs and health professionals advise women to be “selfish”, to be assertive saying “no”, or active in asking for help. However, an ill woman should not need to say “no” or ask for help for it to be understood that she needs to be taken care of. This discourse places the burden of responsibility and guilt on to women and obscures gendered practices.¹¹

Although I have presented here a few particular cases of how gender influences women’s health, it should be enough to demonstrate that women’s gender roles

¹⁰ See Epstein (1986) for a detailed description of “unspeakable” feelings after treatment.

¹¹ I borrow this idea from Celia Kitzinger and Hannah Frith’s (1999) work on gendered discourses and practices around refusal skills.

(sometimes pathogenic to quote Helman), and not biology, ignorance or cultural beliefs of the working class, lie at the heart of explanations why women cannot fulfil the obligations of the sick role described by Parsons, nor enjoy the right to be ill. I am interested in exploring how gender influences not only women's ill-health behaviours but also the relationships of women with their (male) partners and families. I am also interested in looking at how gender plays an important role in shaping access to health care and the quality of care received.

2.3.3. Age and Breast Cancer

Age is a no less powerful factor in shaping breast cancer as gender. Age receives little or no attention either in the Spanish research on women and health (Castaño and Martínez-Benlloch 1990: 160), nor in the British research on health (Marshall 1990: 31; Henwood 1990), not to mention in the breast cancer discourse. Too typically, and quite erroneously as this work also reveals, because breast cancer is identified with sexuality issues and youth (see Saywell, Beattie, and Henderson 2000). As a result, the aged breast cancer patient is often invisible both in research and in practice, when in reality the largest proportion of breast cancers affect women aged 50 or over. This comprises about 80% of all the breast cancer cases (Macmillan Cancer Support 2008).

In this thesis, an 'older' woman is defined as one over the age of 50 or who has undergone menopause. Adopting this definition does not mean that I agree with it, but for expediency in this case I follow cultural (ageist) understandings and conceptions about women (see Hunt 1994; Gannon 1999) which often frame the access to treatment and the quality of care received, as this thesis attempts to unravel.

One concept in relation to the impact of age in health inequality which should be emphasised here is that of ageism. Ageism is the discrimination of persons on the basis of their age. According to Scrutton (1990: 12), although ageism is a social construction it grants its legitimacy upon the naturalization of the pathologisation of ageing (McEwen 1990), or to use DiGiacomo's (1999) expression, upon the medicalization of cultural beliefs about ageing.

In this sense, biomedicine defines ageing as the cause of a multitude of dreaded health problems such as lack of social engagement, loss of mental activity or loss of autonomy which lead to dependency and senility (Greengross 1990), and asexuality. Thus, provision of resources and the manner in which services are provided are very

much based on assumptions about “the quality of health which can be expected in old age” (Henwood 1990: 43).

In women the process of ageing is more problematic than for men as it is powerfully embedded with sexist ideas about the female body (Arber 1998). Menopause is the sign of ageing. It is treated as the cause of loss of womanhood, psychiatric disorders, ugliness and loss of sexual activity (Gannon 1999). This argument is reflective of the belief that a woman’s status and identity derive primarily through her capacities to bear a child (Eckman 1998). Therefore, once that a woman stops menstruating, their ovaries are regarded as “useless” as they are not longer fertile (Hunt 1994; Webster Barbre 1998). According to this model, during “menopause a tragedy takes place: a kind of premature death” (Greer 1991:1) because women become “incomplete human being[s]” (Crawford 2004: 25) which cannot satisfy phallic goals (Pauly Morgan 1998: 151). These beliefs may help the reader to understand why older women receive fewer treatments like chemotherapy or radiotherapy and instead undergo more radical surgeries like mastectomies and hysterectomies (The Hysterectomy Association 2010) than younger women, or why they are excluded from cancer screening after the age of 65 in all but three ACs (e.g. Navarra, Valencia and Catalonia) despite the fact that breast cancer increases with age, and that the life expectancy for Spanish women is 87 years.

As emerged from the experiences of women I spoke with, the impact of age in health outcomes should not be analyzed in isolation, but in interaction with other social forces. When age combines with class and gender there are also significant differentials in health inequality. For instance, older people who are not entitled to pension schemes or whose earnings, savings or pensions are insufficient to “make ends meet” face serious social and economic strains (Lautsch and Scully 2000; Navarro 2006: 93-105). They must make the adjustments necessary to stretch their income to the point that among those in more disadvantaged socioeconomic circumstances it becomes a veritable quest for survival¹². Further complications arise if they have to care for the family or deal with the economic burden of divorce, illness, disability, or widowhood.

¹² Navarro (2006: 96-97) analyses the precarious state of pensions in Spain, which hits older people more dramatically. He states “numbers do not lie. In 2000 the average occupational pension was of 625,28 Euros per month. Widowhood pensions are even lower. In 2003 it was of 397.96 Euros per calendar month.”

Besides, old people face discrimination in the labour market adding more stress to this situation of vulnerability (Hult and Edlund 2008; Laczko and Phillipson 1990).

Poverty leads many older people to save money on basic necessities such as heating, electricity, or dietary bills, triggering behaviours which can lead to ill-health and ultimately premature death. Ironically, despite the fact that older people have greater freedom in terms of time, their financial situation constrains social participation and leisure, as Siegrist (2009) notes that old people not only have fewer financial resources enabling them to socialize, travel, join fitness or leisure clubs, but are more likely to spend time at home increasing the likelihood of developing mental and physical problems. The realities of many older people's lives often does not match up with the ideal that the third age is for engaging in leisure activities essential for "healthy ageing" (López Sánchez 2003: 20).

Arber and Ginn (1991) note that the triple burden of age, class and gender is more pernicious for women than men. The accumulation of economic, personal and social past realities disqualified the majority of women of the older generation in Spain to enter education because women's place was at home. The consequences were that many of these women were dependent on their husbands and, at present, have low pensions, or none at all.

2.3.4. Social Class and Breast Cancer

Despite the fact that the British NHS is based on the core principle of universalism, the role of class in determining the health status among breast cancer patients in the UK was made clear ten years ago by The Cancer Research Group Campaign (Davey, Austoker and Macleod 1999). The summary of the work indicates that there are some considerable differences in morbidity and mortality as a consequence of breast cancer between richer and poorer women in the UK. The study found that women from the lowest social strata had lower survival rates, tended to wait longer until their sickness progressed before they sought help, had greater co-morbidity, had more emergency and hospital admissions, and finally, needed more psychological support than women from more affluent groups. On the contrary, they found that more affluent women tended to ask more, and more articulate questions than women from lower classes. Hence, they were better informed, received better treatment, and made better use of the resources available.

As this study revealed, there are inequalities in diagnosis, treatment, care and health outcomes between rich and poor women which raises the question of *why* the health of poorer women should be lower than that of better-off women. Although the study hinted at some structural factors that may condition these outcomes, it concluded that “there is mixed evidence” meaning they were unable to offer decisive conclusions. Further research is needed in this sense, and this thesis attempts to offer a new glimpse of the ways in which social class affects the experience of breast cancer.

Essentially, the traditional argument is that lower class people choose to engage in unhealthy behaviour because of their ignorance, or cultural beliefs (Bayne-Smith 1996: 5; Nigenda and Caballero 2008 in Knaul et al. 2008: 120). However, there are some studies which have tried to untangle what Williams (2004: 280) terms “the hidden injuries of class”. These studies have illustrated how very particular social conditions of women are the cause of unhealthy behaviours.

Seeking care can be seriously impeded by family responsibilities and by the costs of treatments and displacements (Stolley et al. 2006; Kasper 2000). Needless to say, arranging childcare or care for the dependents is more difficult, if not unaffordable, for poorer women than for more affluent women. Also, poor women in precarious jobs may find it more difficult to leave the workplace for checkups and treatments. These situations lead to psychological stress and greater co-morbidity. The more the woman delays seeking care, the more likely she is to require more aggressive treatment, increasing the chances of complications, as well as reducing her chances of survival. Greater co-morbidity can also be due to undermedication or autodossification of drugs if the patient has to pay for the treatment (Desclaux 2004; Scheper-Hughes 2000). Besides, poorer women use less the benefits of CAM to manage the side effects of treatment because usually it is very costly (Boon et al. 1999).

Bayne-Smith (1996: 13) argues that “inequality cannot be envisioned solely in terms of income level and what that income can purchase”. Compounding the burden of lack of financial resources is the fact that poorer women are more likely to lack support and quality of care from health professionals. Experiences of patronization, discrimination or infantilisation closely linked to classist attitudes may affect patients’ health seeking-behaviour (see Becker 2000). On the one hand it may fuel distrust of the biomedical system which affects compliance and follow up (Ong 1995). On the other hand it may impact negatively on women’s confidence and self-esteem.

Given these multiple and varied examples, the main controversy over how to include the impact of social class revolves around which criteria to use to define and classify it (Kerbo 1991:13; Devine 1997:19). In what follows I will briefly explore literature and debates around social class so that we can understand the various ways in which breast cancer patients' social class operates in creating health inequality.

Two main theorists who have influenced modern thinking on social class are Karl Marx and Max Weber. According to Marx, the current social strata are comprised of the bourgeoisie and the proletariat. The former controlled the means of production and exploited the latter who had to sell their labour power in order to survive (Borrell et al. 2004b:76).

Weber went beyond this analysis and suggested that power, knowledge (e.g. qualifications, skills) and social status were as important as the ownership of the means of production (Borrell et al. 2004b: 76). Thus, for Weber it is imperative that social class be understood, and hence analyzed, as a "multifactorial entity" (see also Abbott and Sapsford 1987:19; Bettie 2003; Zmroczek and Mahony 1999).

More recent attempts to re-categorise class are the classifications put forward by Goldthorpe and the British Registrar General (RG)¹³. Both classifications are based on a person's (usually the male breadwinner's) occupation and skills. It distinguishes different groups which range from managerial occupations at the top to unskilled occupations at the bottom (OPCS 1991 in Annandale 1999: 103-105),

Despite these developments in the categorization of class, some authors suggest that focusing on the husband's occupation as the only unit of analysis obscures ageist, gender and classist bias that have failed to account for women and old people as subjects of research. The first critique draws attention to the fact that research only focuses on people of working age, assuming that older people are "a homogenous group, all inevitably sick and in need of health care" (Victor 1991 in Annandale 1999:107). The same happens with women "who bore and cared for children [but] had no 'objective' value placed on their work" (Jordanova 1981). Another criticism is that these models also fail to recognize that many women do engage in paid work outside home, and for many of them working is not a pleasurable choice but an urgency (Doyal

¹³ The British Registrar General is the model used by the Spanish Society of Epidemiology (Grupo SEE and Grupo SEMFyC in Borrell,et al.2004b: 76).

1995: 152). Moreover, they fail to recognize that many households would come near the poverty line without the wife's wage (Land 1976:119 in Wajcman 1981:11).

Abbott and Sapsford (1987:17) also highlight that there are other aspects which these class schemas ignore. They argue that many women's positions in the labour market may not reflect their class position. For instance, graduate women may find it difficult to pursue their careers as a consequence of the demands of (gendered) domestic work and childcare. Thus many women, especially those with small children, may have to accept working in part time jobs which often do not correspond to their qualifications or possibilities. Often, part time jobs are low paid, insecure and allow women little chances for promotion. According to Abbott and Sapsford, women by virtue of their gender are at the bottom of the hierarchy of employment. This is the reason that, they argue, women by virtue of their gender are a social class in their own right (Ibid: 4-10).

To overcome the invisibility of women there have been some attempts to incorporate them into the analysis of class. Borrell et al. (2004b) summarize the inclusion of women in class analysis in two basic propositions. The first one would be "the dominant proposition" based on the most privileged social class in the household. The second proposition would be "the individual's proposition" which takes women's class into account based on their occupation.

However, these categorizations are still problematic because they fail to account for the importance of, as Weber pointed out, power, knowledge or social status. For example, someone may not have "cash" or property, but may be very influential or have high social status because of other socio political circumstances. In this sense Bettie (2003) notes that class is not just about money: class is a culture and is performative. She states:

[Class] is manifest in styles of speech, accent and body language. It refers to the fact that class subjects are the effects of the social structure of class inequality, caught in unconscious displays of cultural capital that are the consequence of class origin or habitus.

As I mentioned above, these performativities are key to understanding health professionals' practices of infantilisation, discrimination or patronisation of patients who are from lower social positions. Maribel Blázquez Rodríguez (2009), in her

research on pregnancy and birth in Madrid has shown the importance of looking at class from different angles if we want to obtain a more holistic picture of how it impacts on women's health. For example, she found out that women with higher levels of education not only had more resources to navigate the health system, but were more likely to "be acknowledged by the health professionals and receive more and better information" (Blázquez Rodríguez 2009:128). To sum up, lower class women are more likely to be more disadvantaged in terms of access to resources and in terms of quality of care received (see Kasper 2000).

In this thesis I propose to look at the many nuances in the understanding of social class. That is to say, I look at women's class in terms of educational background and occupational skills as well as to their economic class. This approach, I believe, allows us to "do justice" to women's present situation as it takes into account the complex intersection of women's personal trajectories and agency with the historical effects of their gender biographies which, to a certain extent, have defined women's class position.

2.4. Theorizing Breast Cancer from Embodiment and Experience

Much has been written about the experience of breast cancer. Beginning in the early 1970s, and with increased energy with the onset of the Internet, autobiographical accounts of breast cancer (or lay knowledge) have influenced the way we think about cancer, and in doing so, have influenced theory and policy making.

Until the '70s, accounts of breast cancer, whether they were medical reports, psychological reports or media coverage, were biomedical and represented social fantasies about the ideal breast (Ferguson 2000; Zavestoski, McCormick and Brown 2004). Sue Wilkinson and Celia Kitzinger warn us that it should not come as a surprise that breast cancer occupies a central place in the cancer and beauty industry given, not only its incidence, but the importance of breasts as objects of male sexual interest (Wilkinson and Kitzinger 1993, 1994, 2000; Wilkinson 2000a, 2000b, 2001).

First publications of personal narratives of breast cancer emerged as a form of resistance to conventional social forms of depiction of breast cancer (Rosenbaum and Roos 2000). They were supported by The Women's Health Movement (Couser 1997: 39). At the core, these narratives aimed at challenging biomedical practices and

assumptions *from* experience. For one thing, authors of such narratives had a political desire to make public the invisible experiences of breast cancer. to reach or to empower as many women as possible, so that they could benefit from knowledge legitimated by embodied experiences of illness. By invisibility I refer not only to incidence, but to the experiences of “loneliness and terrorism” of treatments (Spence 1988: 150), alienation, prejudice (Matuschka 1994; 1997a,b, 2003), objectification¹⁴, inaccessibility of medical jargon (Pitts 2004), and to the social pressure to conceal any evidence of fear or illness to protect family members (Wilkinson 2000: 232).

For Audre Lorde speaking out is a call for action: it is a way of sharing knowledge, raising consciousness and generating/engendering agency in decision making and illness management. She wrote in her introduction to *Cancer Journals*:

I am a post-mastectomy woman who believes our feelings need voice in order to be recognized, respected, and of use (...) For other women of all ages, colors, and sexual identities who recognize that imposed silence about any area of our lives is a tool for separation and powerlessness, and for myself, I have tried to voice some of my feelings and thoughts about the travesty of prosthesis, the pain of amputation, the function of cancer in a profit economy, my confrontation with mortality, the strength of women loving, and the power and rewards of self-conscious living (Lorde 1997: 7-8).

Similarly, for Matuschka, her art work was a cancer campaign aimed at “bringing attention to the silent epidemic”. But at the same time, the images of her mastectomy were an urgency to change the discourse of bodily ugliness and by doing so, dignifying breastless women.

According to Lorde, the lived experience of telling stories of breast cancer was linked to the process of healing (Garro and Mattingly 2000) and it was “liberatory” (hooks 1994).

There are two important features of these personal narratives relevant for my thesis. The first one is their political nature, a characteristic that I will explore in more detail in Chapter 3. These narratives not only make visible breast cancer, but also point to a

¹⁴ Betsy Noorzay (1990) powerfully gave expression to her feelings of objectification through her poem “I’m being cut up and served like a turkey, the main course. I’m not a person. I’m a piece of meat”.

concern with something more than just body image problems as a consequence of mastectomy, therefore challenging social assumptions that this is patients' main concern.

The second one relates to the discriminatory face of narratives. Thomas Couser (1997:38) argues that even narratives, which are supposed to be public and liberatory, do discriminate on the basis of ethnicity and class, as voiceless women remain unvoiced. In this regard, my thesis attempts to open up the political imaginary for Spanish breast cancer sufferers whose embodied knowledges, experiences and critiques have been repeatedly silenced by the social structure, especially because the empowering use of the Internet (Pitts 2004) is out of reach of many Spanish breast cancer sufferers who are over 50.

What I would like to briefly explore in this last section is how women's embodied knowledge has provoked debate about breast reconstruction and the mindful breast in feminism and social sciences. Here, I would like to call attention to the fact that although I focus only on theory from "the breasted experience" (Young 1990), my thesis is equally interested in women's embodied theorizing on other arenas of breast cancer. Indeed, my task in this thesis is to reflect the experience of women viewed as a spoken theory.

2.4.1. On Breast Prosthesis and Breast Reconstruction

Given that women are expected to be the object of the male gaze, are expected to beautify themselves in order to become loveable, are still fighting for basic rights over their own bodies, it seemed to me that the breast could be seen as a metaphor for our struggles (Spence 1986: 155).

There are two main competing discourses around breast cancer patients' sexuality: medical knowledge based on an androcentric and Cartesian understanding of the breast, and women's knowledge based on (dis)embodied experiences.

As I mentioned earlier, in psychology and biomedicine there is a reductionist view of sexuality that equates women's sexual functioning with the look and size of their breasts and, in fact, a substantial part of the research (and media coverage) on the topic has concentrated on this aspect, as Jo Spence intimated in the opening quotation. The

assumption is that breast loss as a consequence of mastectomy is the chief cause of women's sexual problems (narrowly defined as body image problems, loss of self-esteem and marital unhappiness) (Christensen 1983; Fobair et al. 2006; Bartmann 1996). With this understanding of women's sexuality in mind, breast prostheses and breast reconstruction are thought to have positive impacts on women's well being because they address "women's *main* needs" (Thorne and Murray 2000: 151). That is to say, breast reconstruction and breast prosthesis are believed to alleviate women's damaged female identity, thus restoring their sexuality (Zimmermann 1998: 65).

Taking quite the opposite view, feminists, well-informed by experience, emphasize that this perspective obscures the fact that diverse interests are articulated around breast prosthesis and breast reconstruction, while ignoring basic questions such as asking women how they feel about their breasts (Wilkinson and Kitzinger 1993; 1994).

The main critique is that breasts are regarded as objects of men's, not women's, sexual pleasure (Blum 2003; Sedgwick 1994; Spence 1988). This is manifest when the emphasis is on how women should ideally look, rather than how women actually look and feel about themselves and their breasts¹⁵. In some cases the quest for the ideal breast legitimates extreme *bilateral prophylactic mastectomy*. In theory this procedure is done as a preventive measure in practice, Sue Wilkinson and Celia Kitzinger noted that healthy breasts can be amputated in order to achieve a more aesthetic breast surgery:

My own second mastectomy, performed at the time of breast reconstruction, was prophylactic. My surgeon said he could not offer a 'good match' after reconstruction unless both breasts were reconstructed and I allowed myself to be swayed to his belief. Now, I regret sacrificing my healthy left breast, If I had to do it again, I would not trade a healthy, functioning breast just to try to achieve what a surgeon calls a 'better match'. It is a lasting regret. I could have breast-fed our son if I had resisted that surgeon's coercion (Jonson 1987: 101 quoted in Wilkinson and Kitzinger 1994: 128).

¹⁵ Florescu (2006: 287) questions the emphasis on the look and argues that "ironically, while women who have lost a breast to mastectomy are recommended to reconstruct that physical loss from the (fat) tissue of their buttocks or belly, women who have experienced hysterectomy are not recommended anything surgically to replace the loss of a uterus (...) erroneously putting an emphasis on the appearances and not on the body per se, as a whole".

This aggressive practice highlights how the male-orientated and Cartesian biomedical understanding of the breast reconstruction reduces the breast to an object which is thought to be easily changeable: “like watches, indefinitely repairable if one has at one’s disposal enough spare cogs” (Moulin 1995), rather than as a site of lived experience (Csordas 1994) or a bodily extension of the self (French 1994; Hogle 2005; Reischer and Koo 2004).

Ferguson (2000: 70) argues that the medicalized idea that breast prostheses and breast reconstruction are a must for all cancer patients has been so successfully marketed that it continues to be heavily recommended by health professionals. Indeed, Ferguson notes that it has become part of “the definition of breast cancer treatment”. According to the author, this assumption reinforces several damaging ideas. First, that breasts are the foundation of women’s womanhood. Therefore, it buttresses the idea that women are just bodies with breasts.

Second, Wilkinson and Kitzinger (1993) argue that biomedical emphasis on words like disfigurement, mutilation, deformity, and “defect” (Schon 1968) conveys the message that women’s bodies are repulsive. Audre Lorde (1997), Matuschka (1994, 1997a, 1997b, 2003) or Kohlman (2006a, 2006b) who claimed the right to mourn the loss of their breast, and who refused to have their breasts reconstructed after breast cancer, endured social hostility towards their “unruly” bodies. They had to defend themselves against fierce attacks from those who defined them as butch, anti-erotic or in denial (see also Cassel 2001). Audre Lorde (1997:65) who observed that “the idea that a woman can be beautiful and one-breasted is considered depraved, or at best, bizarre, a threat to ‘morale’” .

Further, Ferguson (2000) argues that desire to recreate the perfect breast for men’s pleasure is exposed when biomedicine does not tell women of the many serious risks associated with breast reconstruction. For example, the life of a breast implant is finite. The average life is 12 years and after that time women will have to undergo surgery again in order to replace the implants. Second, breast implants are delicate. They can deflate, leak or break, for instance, during mammography sessions as the breast has to be compressed with a paddle in order to examine the maximum tissue possible. Again, if the implant breaks this would entail surgery to remove the prosthesis. Third, breast reconstruction is a painful and debilitating process. Besides it does not restore magically the aureola and the nipples. Thus if women want to have a more “aesthetic breast” they

need to undergo further surgery with all the subsequent risk of complications. Often, surgeons do “NOT mention that this may entail using skin from the remaining nipple or the labia” (Faulder 1989 in Wilkinson and Kitzinger 1993: 231). Fourth, breast implants may hide tumours from the gaze of the mammogram. Fifth, currently there does not exist a breast implant which is completely *biologically inert*, that is to say, that does “not deteriorate or cause reactions in the body” (Bridges and Vasey 1993; Guthrie and Podolsky 1994 in Ferguson 2000: 61). As a consequence women may develop a lengthy list of *real* health problems associated with implants which are often overlooked or ignored. Arthritis, rashes, necrosis of the reconstructed breasts, lupus, joint pain, stiffness, swelling, chronic fatigue, hardening of the breasts, breathing problems, and ultimately cancer are just but a few side effects of breast reconstruction (Ferguson 2000; Zimmermann 1998; Jacobson 2000). Finally, the pictures of (transformational) restoration miracles are incomplete ones. The experience of breast reconstruction is often explained in terms of restoring beauty but not in terms of feeling, sensitivity or embodied pleasure for women (Wilkinson and Kitzinger 1993, 1994).

2.4.2. Ways of Knowing: The Breasted Experience

Women’s theorizing on breast cancer was (and is) not aimed at dismissing or ridiculing the possible therapeutic effects of breast reconstruction or breast prosthesis; rather it is driven by the desire to call attention to the experience of having breasts as a source of incommensurable pleasure and embodied self for many women. Lorde (1997: 8), reflecting upon the implications of prosthesis and with a sense of respect for women’s choices, said poignantly:

It is not my intention to judge the woman who has chosen the path of prosthesis, of silence and invisibility the woman who wishes to be “the same than before”. She has survived on another kind of courage and she is not alone.

As we have seen the prevailing assumption is that breasts have a merely dual function: that of lactation and that of erotic decoration to stimulate men. Indeed, breasts are mainly portrayed as sexy appendages for seducing male partners. So entrenched is the

popular belief that the value of the breast is purely visual, that the reconstructed breast has been defined as a “dildo” (Broom 2001) or “eye candy” (Pedersen 2004), whose mere aim is arouse women’s *male* partners. For many scholars like Sue Wilkinson and Celia Kitzinger (1993; 1994) Audre Lorde (1997), Nina Hallowell (2000), and Dorothy Broom (2001), to name but a few, it is paramount to acknowledge the fact that breasts are more than just beauty and aesthetics. Iris Marion Young (1990) calls attention to the fact that the breasted experience allows women (and men) to apprehend the world through their breasts. The breasted experience is a way in which women exist in the world, it is how women apprehend the world. Thus, false breasts cannot restore the capacity to feel the outer world. For that reason it is imperative to acknowledge that the loss of a breast is a tremendous trauma for many women.

Nancy Scheper-Hughes and Margaret Lock offer a useful concept to understand what Iris Marion Young (1990) calls “the breasted experience”, or embodied significance of breasts for many women which challenge mechanical understandings of the breast. They refer to the “mindful body” in order to describe “the sense of body-awareness, of mind/body integration, and of being-in-the world” (Scheper-Hughes and Lock 1987: 14). From the very first moment of our existence we feel and understand the world through our body.

The example from Hallowell’s (2000: 170-173) research with women who underwent prophylactic surgery followed by breast reconstruction may illustrate the concept of the breasted experience. For example, the fact that false breasts do not “manoeuvre” and do not mould to other’s body when touched was expressed by the women in Hallowell’s study as uncomfortable and alienating. False breasts were perceived as “blocks” or a “barrier” when they were hugged or caressed. The crux of breast reconstruction was felt when women’s husbands got aroused when touching their breasts, but they could feel nothing. This disembodiment made women feel upset and alienated from their breasts which in turn affected negatively their libido.

Although scarce, narratives of the breast reveal that many women delight themselves in the pleasure of breastfeeding¹⁶. Many other women find pleasure when their breasts and nipples are being rubbed, caressed, squeezed and sucked to the point of orgasm (Greer 2000: 60). Nonetheless, Cartesian *and* androcentric understandings of

¹⁶ See Young (1990:199) and Traina (2000: 369) for beautiful descriptions of their erotic experiences of breastfeeding.

the breast deny the fact that for many women breast loss implies the loss of a loved part of themselves and the loss of pride for a bodily part (Chapkins 1986). Indeed, for Young (1990), a breast cancer patient herself, what matters most is the feeling and sensitivity of the breast not the appearance.

Yet, as we have seen, this “alternative” way of knowing the world has produced little change in some basic working assumptions about women’s sexuality and women’s breasts when it comes to research and biomedical practices. Following these writers, I argue that through disembodied sexual and erotic experiences, as well as the violently painful embodiment of treatments, women demand an “undefinition” (Hite 1993: 33) of oppressive and reductionist medical concepts.

2.5. Conclusion

My study of the experiences of Spanish breast cancer patients and survivors brings into sharp focus all the issues cited in this chapter. The preceding reflexive exercise of reviewing an important part of the rich literature on breast cancer reveals a number of possible ways to contribute to the research on breast cancer, including the following:

- (1). Attention to Spanish women’s experiences of breast cancer in order to explore how their narratives speak culture (Riessman 1993: 5). That is to say, how women’s experiences of health and illness highlight the need to take into account the intersection of biomedical understandings of health, cultural assumptions, societal values and historic-political processes.
- (2). Attention to how women’s theorize from “embodied experience” and how this knowledge may clash with biomedical understanding of health.
- (3). Researching how cultural assumptions permeate biomedical discourses and practices and the implications of this in shaping access to health care and the quality of care received.
- (4). Attention to the need to analyze gender in interaction with other social forces such as social class and age, to offer a much richer understanding of the complex phenomena which shape the experience of breast cancer.

The methodological approach that is most suited to address the missing “competing” discourses of Spanish breast cancer sufferers is critical ethnography. In the next chapter

I will discuss how a narrative approach necessitates a feminist and critical ethnographic approach focused on what matters most to women. From my point of view, it is essential to consider women as active agents in the production of legitimate knowledge. Hence, it is paramount that women “generate their problems”, and that the research questions are not dictated by the perspective of the researcher. These are very sensitive issues given the power relations within the research relationship which shape the narrative encounter, and the academic “blindness” which may prevent me from hearing what women seek to convey beyond the “disguise” of illness narratives or politically correct discourses. I will address these key methodological issues in the following chapter.

Chapter 3

Doing Feminist Ethnography on Health Research: Methodological Issues

3.1. Introduction

The focus of this chapter is on the methodological issues concerning my research and experience of doing fieldwork on a medical topic, from a feminist standpoint, and about a sensitive issue, in Spain. Although a number of studies have employed ethnographic methods to explore different issues shaping the experience of breast cancer, I could not find any examples from Spain. My study contributes in this regard by presenting the lived experience of Spanish women living with breast cancer.

I begin by describing various epistemological positions. I explain how a feminist and critical ethnographic framework complements the overarching theoretical narrative framework that has guided my research, the collection and analysis of data. This chapter places emphasis on reflexive issues such as: the difficulties experienced in getting access *into* the field; how I chose the sample; and how the process of fieldwork limited my access to informants. I consider some issues around my concern with minimizing the hierarchical relationship between myself as a researcher, and those I researched, which in turns raises dilemmas as to how to make a contribution to knowledge while representing women's voices. Finally I explore how I came to realize my class (un)consciousness when I listened to women's accounts.

3.2. Epistemological Positions: Locating Myself in the Research

This thesis is a political narrative of breast cancer in Spain. Working on such a project, as a feminist and as a scholar who has the power to criticize, or on the contrary to legitimate the “established hierarchy of Knowledge”¹⁷ [added capital K] (Becker 1967: 242), I feel I have the obligation to take political and ethical responsibility for my work

¹⁷ I employ the term “hierarchy of knowledge” to signify how certain kinds of knowledge, ideology and practices dominate over others by claiming their status as universal and truthful (Gordon 1988).

by engaging in practices that empower those who are being studied (Walter 1995; Scheper-Hughes 1990). This requires a justification of my epistemological views because, as Alderson points out: “theories are at the heart of practice, planning and research” (1998: 1007). In what follows I will explain how these *standpoints*¹⁸ are situated with regard to theoretical positions and how they have guided my position within the research, and the collection and analysis of data.

3.2.1. Feminist Approaches in Research

My standpoint is heavily informed by feminism. As a feminist I see the world appallingly dominated by discriminatory structural forces which affect people’s experiences of health and well-being. Yet, I believe in a world where all people, regardless of their gender, class, religion, age, race, bodily ability, or political ideologies are treated as human beings. Fundamental to feminism (although not exclusive to it), and central to this thesis, is a concern with policing personal narratives of injustice. Nancy Datan, a feminist who died of breast cancer, emphasized the need to personalize and make visible the experiences of those who are oppressed. She urged feminists to take action:

It is a central tenet of feminism that women’s invisible and private wounds often reflect social and political injustices. It is a commitment central to feminism to share burdens. And it is an axiom of feminism that the personal is political (Datan 1989: 175 in Wilkinson and Kitzinger 1994: 124).

Fundamental to policing are two issues: that of identification, and that of change, of those situations which create inequality. The issue of how to name and frame inequality is far more complex than it may seem at first sight. It requires the exercise of self-inquiry to avoid the unfortunate replication of assumptions (dominant rationality or Knowledge¹⁹) which produces inequality. That is to say, that in conducting research we must grapple with pervasive cultural beliefs that might limit our ability to see beyond

¹⁸ Frank (2000) credits the concept “standpoint” to Dorothy Smith (1987). He wrote: a “standpoint ‘both reflects one’s own unique experience and asserts membership in a community who understand shared experiences in mutually supportive ways’” (Frank 2000: 356 in Thomas 2010: 653).

¹⁹ Sandra Harding has made this point repeatedly. She defines knowledge as “a culture’s best beliefs” (1991: 119).

our immediate experience. This is a key issue because, as Spike Peterson and Sisson Runyan (1993: 1-3) warn, researchers' rationale, which translates into how I look at things, and hear and interpret women's narratives, is highly determined by experience and knowledge (mainly informed by academic writing which can in turn be biased). They argue that "we tend to believe we are seeing 'reality as it *is*' rather than as our culture or discipline interprets or 'maps reality'". In this sense, reflexivity is a powerful methodological tool aimed at questioning the objectivity of my knowledge, assumptions, or stereotypes.

Reflexivity is concerned with basic questions about the ways in which knowledge is produced, the dynamics of power relations within the research relationship, as well as with the representation of participants' voices (Mauthner 1998: 47). For example, feminist scholars have highlighted the need to take into account the ways in which power and knowledge are legitimated, gendered (Walter 1995), classist and racist (Mullings, 2000), and how this leads to inequalities in health (Standing 1997; Doyal 2002).

Susan Harding, in stressing the importance of questioning the dominant rationality underlying any type of research, contends that: "strong objectivity requires what we can think of as 'strong reflexivity'" (1996: 244 in Sampson et al. 2008: 921). It is now axiomatic in ethnographic presentations to pay attention to this issue (Abu-Lughod 2000).

The issue of how to alter situations of inequality is also paramount for feminism. This has in itself constituted some of the dilemmas I will discuss more generally in this chapter. As Nancy Datan pointed out, the most powerful way of challenging inequality is by making women's own experiences central by "positioning women as actors in their own lives" (Hammarström 1999: 242). This is particularly so because women's voices have been repeatedly excluded from public and academic discourses (Standing 1998; Moore 1988; Lewin 2006), as Chapter 2 showed.

Another way of challenging inequality is not only by making visible women's experiences, but by theorizing from their experience (hooks 1994). That is, lay knowledge is thought to be essential for analyzing and criticizing the structural forces that determine women's oppression. Harding (1991: 106) calls for a (re)thinking from women's lives:

Never had women been given a voice of authority in stating their own condition or anyone else's, or in asserting how such conditions should be changed. Never has what counts as general social knowledge been generated by asking questions from the perspectives of women's lives.

In the feminist view, such an approach is a political act *par excellence*.

3.2.3. Critical Ethnography

My theoretical approach is also influenced by critical ethnography. It is important for the reader to recognize that critical ethnography is not as much as method of data collection as a theory of knowledge or method of inquiry (O'Reilly 2009: 52; Scheper - Hughes 1990). This requires that critical ethnography be understood as a way of apprehending and approaching the world; as a way of thinking and acting, not as merely a good tool to obtain data.

Popular descriptions of anthropology define ethnography as the study of societies in order to understand and describe their actions, rituals, organizations and cultural beliefs. The familiar picture often represents the image of a white ethnographer in an exotic culture at the beginning of last century (Martin 1989: 3). In line with this picture, the prototypical ethnographer would spend long periods of time in the field observing people, "and writing information about what they say and do in their home communities and workplaces" (LeCompte and Schensul 1999: 11). All too often, in this portrayal there is a conflation of method and theory (see Madison 2005). Nowadays, although ethnography is the hallmark of anthropology, it is not exclusive to it, and it is widely used both as a method of data collection and as a theoretical approach by many other disciplines such as sociology, education, health sciences, gender studies, social psychology, or development studies, to name but a few.

Willis and Trondman (2000: 10), in their *Manifesto for Ethnography*, highlight that ethnography should not be concerned only with capturing "culture", but also "the social", both in relation to the individual's "sense of lived-out-ness", and the lived experiences of a particular group. From this perspective, "traditional" ethnography was criticised precisely for its disengagement from the subjects of study. Persons were regarded as merely inexpressive bodies. Knowledge produced by actors was, and still is,

according to Paul Atkinson²⁰ and others (e.g. Fine 2003: 54), understood as unauthentic and biased. Moreover, Atkinson contends that an approach which does take into account knowledge produced by individual persons leads to a methodology which is political, thus unscientific.

In contrast, this argument has been challenged on two levels by many social scientists. First, as Becker strongly pointed out, “value freedom or objectivity is not possible and that ‘we cannot avoid taking sides, for reasons firmly based in social structure’” (Becker 1971:213 in Roberts 1997b: 16). Second, this “dehumanizing” approach, in Shore’s view, is contrary to the ethnographic enterprise²¹. Indeed, an ethnography of the social should pay special attention to subjects’ voices (Reyes Cruz 2008; Kleinman 1988, 1992, 1995a). In a key statement about the detachment of the ethnographer, Shore states:

[Anthropologists] tended to give us disembodied system, structures or programs - knowledge without any particular knower in mind and structures of thought that lacked any flesh-and-blood-thinkers. Real people were replaced by hypothetical entities, ‘the savage mind’, the ‘typical’ or ‘average’ members of a community. People appeared more as the passive sites of cultural programming than as purposeful agents, strategists and meaning makers. We came to know more about cultural systems in general than we did about people in particular” (Shore 1996: 54 in Garro and Mattingly 2000: 20).

Critical ethnography has its roots on these debates about power, knowledge production and representation. And as such it shares many of the principles of feminist research on social sciences. Nancy Scheper-Hughes (1990), one of the most famous advocates of this paradigm, argues that “affliction” or social suffering must be the central tenet of critical ethnography. From that start point, human experience is what must “generate problems requiring sociological explanation” (Smith 1987: 84). In doing so, the aim is three-fold: voice participants’ concerns, describe their suffering and understanding the

²⁰ See Carol Thomas (2010) for an interpretation of the debate between different theorists’ approaches to illness narratives as a paradigm or method of data collection.

²¹ Arthur Kleinman and Joan Kleinman (1995b: 96) advance a similar argument to Shore’s. They argue that when the anthropologist distances him/herself from the experience, he/she is “at risk of delegitimizing their subject matter’s human conditions”.

structural forces that shape the individual's life choices and constraints (Farmer 1996, 1999, 2005; Scheper-Hughes 1989) in order to foster social change.

Critical ethnography in the field of health research is particularly concerned with the inequalities in access to health care (Baer et al. 1997; Gold 1977; Declaux 2004; Inhorn 2006); the legitimization of the medical establishment as producer of knowledge and agent of social control (Csordas 1998; Fassin 2004); and the political economy of health bound up with the medicalization of everyday life –characterized by its “materialism, individualism, independence, pragmatism, empiricism, atomism, militarism, profit-making, emotional minimalism, and a mechanistic concept of body and its repair” (Stein 1990 in Baer et al. 1997: 11).

By problematising the relationship between social structure and social affliction, critical ethnography challenges the way we take for granted the social dimensions of health and illness. Nancy Scheper-Hughes (1990) and Richard Wilkinson (1996) consider that social injustices are political and as such must be documented, described and made visible. As Nancy Scheper-Hughes (1990: 195 in Joralemon 1999: 98) puts it, the role of the social scientist should be that of:

The court jester, that small, sometimes mocking, sometimes ironic, but always mischievous voice from the sidelines, afflicting the comfortable, living anthropology as the uncomfortable science.

Their argument is a sober one: the ultimate goal of critical ethnography is to become a resource to raise consciousness. Attempts to acknowledge the political nature of critical ethnography to foster social change were made by Raymond Firth back in 1981. He stated that the role of the discipline in the policy arena is to “question established positions and proclaimed values” (Firth 1981: 2000 in Joralemon 1999: 100). In sum, as Thomas (1995 in Madison 2005: 1) put it “critical ethnography is conventional ethnography with a political purpose”

To conclude this exposition of my theoretical positioning, I should also make clear why I take a feminist and critical ethnographic approach but I use interviews as my primary method of data collection. I am aware that this approach might seem unorthodox for some readers who are used to think of ethnography as inseparable from “hanging out

with people” where the technique of observation is the main method to gather information.

As I already explained, this is not surprising given that traditionally anthropology has relied upon observation techniques. The archetypal example of this approach is Malinowski’s fieldwork among Trobriand Islanders in 1914. However, as Schensul, Schensul and LeCompte (1999: XVII) put it, interviewing is an equally essential ethnographic method of data collection. Moreover, the authors highlight that observation and interviewing can stand on their own. In other words, they can be used alone depending on the research question and /or problems posed by the field.

In my own project two factors necessitated the use of interviews as a primary method of data collection. First, my feminist and critical ethnographic approach suggested the method. Given that this thesis is principally concerned with how Spanish women living with breast cancer define their own health priorities, a method which asks and listens to women directly about their personal and private experiences and dissatisfactions was mandatory. In my research, in-depth interviews with breast cancer patients and survivors were used as a more egalitarian method not only on ethical grounds as described earlier, but on the grounds that women are the experts of their own health and have agency to set up the research agenda. The choice of this method is supported by Parry (2008), Swidler (2001) and other authors as I described in Chapter 2. In fact, in Parry’s review of literature on breast cancer she highlights the need for research the experiences of breast cancer “as women describe them, as opposed to following traditional or standardized models of research (Loveys and Klaich 1991 in Parry 2008: 223; see also Thomas-MacLean 2004), a gap addressed by this thesis.

Second, fieldwork sometimes interrupts the plan. Of course, I would have hoped to complement my in-depth interviews with other methods of data collection like for example fieldtrips in ambulance to the radiotherapy unit since this came out as an issue of concern for some of my informants. I tried as many strategies as I could to get diverse information but the choice of setting and methods did not depend solely on me. Fieldwork was complicated by my difficulties in finding informants and negotiating access with the AECC Carolina where I was based. Indeed, in Spain, I experienced

issues of power and knowledge in the study of health that many anthropologists, feminists and even health researchers discern in the “arena of health”²².

I acknowledge this issue by explaining thoroughly my difficulties in getting access to the field in the final sections of this chapter, but I emphasise two things here. First, although this information would have been precious to have a more complete or less partial picture of the experience of breast cancer, I was primarily interested in women’s speaking directly about their own experiences with breast cancer. I was not concerned with doing a “chemo-ethnography” to use Knopf –Newman’s expression (2001), nor a “hospital ethnography” (Zaman 2008), a ethnography of the AECC or a study to assess the experiences of women’s husbands and family members. Rather I was focused on women’s experiences of health and illness and how their narratives spoke culture (Riessman 1993: 5; see also Swidler 2001). For this reason, I dedicate all the empirical chapters of my thesis to my informants- based as they are on their fundamentally rich and exclusive knowledge. I posit that interviews served women as a consciously revolutionary “micro-political” opportunity to theorize and openly manifest against some of the tyrannies unleashed by breast cancer. Thus, I argue that women’s narratives stand by themselves as a case study of the complex relationship between individual experiences of breast cancer and the wider social, political and discursive context in which they are located.

Second, it is not my intention to promote or disavow any particular way of doing anthropological research. To repeat, my standpoints applied to the proposed study inevitably led me to adopt in-depth interviews as main method of data collection. Yet, whenever the field allowed me I always sought to complement the interviews with other sources of data which could help me to contextualize the complexities of women’s experiences. These included conversations with the staff at the AECC Carolina, in particular Noelia, Pedro and the volunteers, scientific journals, official NHS reports, AECC reports, AECC printouts, informal interviews with oncologists, the head of Carolina’s palliative care unit, several nurses, psychologists, gynaecologists and some family members.

²² See Wagner (1997) for a fascinating narrative that sheds light on my own experience; See also Savage (2006) and Valls-Llobet and Barranco Castillo 2006

3.3. Emotions as a Tool for Women's Empowerment and as an Ethical Consideration in Gaining Rapport

Certainly emotions were at the heart of my methodological dilemmas. Emotions were present in the ongoing experience of researching on and with women who had breast cancer.

The sensorial experience of interviewing women was dialogically reciprocal. Women shared with me the more intimate aspects of their lives, and at the same time, as a listener, I was inevitably physically and mentally sensitive to their experiences. I could have chosen the role of a robotic, cold and impassive listener, waiting patiently until the end of silences or sobs, moved not by empathy but for more information to come. However, like Kleinman (1988), I chose to listen empathetically²³ to their stories of indescribable pain, anger, frustration, but also joy.

My approach clashed with the hierarchy of knowledge which dictates the protocol of doing “good” scientific research. As I explained before, the belief that the ethnographer should be at the margin is still echoed in many academic debates (see Thomas 2010; Roberts 1997a, 1997b), which often results in “dilemmas that are at once ethical, corporal, intellectual and political” (Hegde 2009: 276), and therefore, risks questioning my credibility (Newton 2006: 174).

The *status quo* of emotions is at once haunted and (de)legitimated by Cartesian ideas about science (Ramazanoğlu and Holland 2000). Science is considered to be objective and neutral, thriving on reason. On the contrary, emotions have been condemned²⁴ as the “antithesis of the detached scientific mind and its quest for objectivity” (Bendelow and Williams 1998: xii in Blackman 2007: 700).

In the idea of maintaining distance from the subject of research there is a contradiction between two of the core principles which sustain this thesis: the political endeavour of minimizing hierarchical relationships between informants and researcher by granting the former agency and voice, and the ethical goal of not using informants as mere objects from who to obtain information to satisfy academic hunger. Emotions then became an ethical and political base for my ethnography. This means that women are

²³ By listening empathically I mean Kleinman's concept of “empathic witnessing”. He defines this as: “the existential commitment to be with the sick person and to facilitate his or her building of an illness narrative that will make sense of and give value to the experience” (1988: 54)

²⁴ Bochner (2001: 141 in Thomas 2010: 652) asked: “Would it be better for sociology to leave people to suffer alone, in silence, confusion, and fear? Shouldn't “good sociology” oppose suffering, promote healing, and give agency to marginalized identities? What does sociology become when the only face it shows is critical, sceptical, dubious, or doubting?”

regarded as “human beings” and not only as a “number” (Sered and Tabory: 1999) or as a “source of data” (Maynard 1994: 16). This issue was, if anything, more important and sensitive in this thesis because breast cancer patients often face situations in which they are alienated, disembodied, and objectified (Spence 1988). Thus, by reducing informants to the status of data I would be reproducing what this thesis precisely criticizes.

Once I gained access to the women, gaining trust from them proved to be easy. I began each interview by asking what name they would like me to use as their pseudonym. I thought that it would be a warm ice-breaker because it gave them the guarantee that their names would be removed from the thesis.

I transcribed the interviews as soon as it was possible in order to facilitate the process of transcribing/coding/analyzing when their words were fresh in my mind. In my final questions I asked women to think of themselves as the Health Minister (*Ministra de Salud*). I also asked them what they would say to a woman who has been recently diagnosed. What advice or suggestions they would give to the woman’s family, friends, society, or even health professionals. I concluded all interviews by asking participants to recall anything they thought essential about their experience of breast cancer which I had missed in my questions. I explained that I thought of them as the maximum authority Health Minister (in cancer-related issues Health Minister) granted by their embodied experience.

The formula of these questions was based on participatory inquiry. Stéphanie Wahab (2003: 630) argues that participative inquiry empowers participants because informants are regarded as “the experts on their own lives, particularly because they have repeatedly been denied the validity of their statements”. This should be understood in terms of the philosophy of the gift proposed by Mauss (1971), and well embraced by feminist ethics. The gift is understood as an interaction between persons that require reciprocity. That is to say, any gift entails that something be given in return. The privilege of having access to women’s lives demanded a gift from my side. My little gift was to seek an “intimate and non-hierarchical relationship” (Oakley 1990: 47) where women’s voices were not only used for my research but voiced (Sampson et al. 2008; Parr 1998; Mauthner and Doucet 1998).

All the interviews were long, personal, touching descriptions of their suffering, rage, sadness, concerns, family problems, but also aspirations for the future. At some

points, most of the interviews were particularly intense and emotional both for the women and for myself, but like Janet Parr (1998: 94-95), I felt “excited” that they were openly sharing their experiences with me.

Despite crushingly heartbreaking moments, I usually felt comfortable in the interviews. Not always though. In one of my interviews I was a bit concerned because I could not get a woman called Saray, extremely reserved, to speak more than monosyllables. My academic training was in social work and social research methods. It was my training, plus my experience of conducting interviews at work, which enabled me to feel comfortable with women’s long pauses and silences, rather than feeling anxious about interrupting silences with new questions. Besides, my questions were made in such a way which made it impossible to answer with yes or no. Still, Saray managed to summarize her experiences in a couple of words. My questioning could not be regarded as anything like the kind of conversation described by Riessman (1993:2) “when someone told in exquisite details what she said, what he said, what happened next - a recapitulation of every nuance of a moment that had special meaning for her”. However, this interview was not similar to any of the other interviews I had ever experienced.

I have mentioned before that I concluded my interviews asking if they wanted to add something meaningful for them which I had left out of my questions. Frequently, the informants acknowledged that they were surprised by the amount of intimate information they had shared with me. Sentences like: “you are able to make stones speak”, “you have good vibes”, “I never spoke about this with anyone”, “I feel comfortable with you”, “I feel relieved now” were common answers to my question. Used as I was to women’s openness made it even more difficult to interview Saray. It seemed to me that I was conducting a monologue.

In recalling this situation, I thought of Katherine A. Dettwyler’s comical vignette about trying to find out about women’s decisions over household expenditure in Mali. After some hard and very stylized interviews which were “almost like pulling teeth” she wondered to herself: “how does anyone ever get decent interview data?” (1994:55). All of a sudden I started joking with Saray: “You are really hard eh? You are making me sweat with your answers!” (*Eres dura Eh. ¡Me estás haciendo sudar con tus respuestas!*). I felt relieved when she replied: “Really? I am talking more than usual!” At the time of writing these lines I can still picture myself rolling my eyes as if to say

“Damm, how lucky I am!” to which we could not help bursting out laughing. In this brief moment I felt I had gained Saray’s confidence. She did not speak much longer sentences, but our interaction, body language, and tone of voice had changed.

After the interview finished and my informant left, my comment disclosing my emotions recurred to me. At the time, perhaps one of the things I remembered more from my degree in social work and anthropology is the “theory” that emotions are not professional. For years I was taught it was not correct to get emotionally involved in my work. As I described above, this credo is not surprising since many of today’s texts still regard researchers’ emotions as a professional failure²⁵.

I discussed my concerns with Noelia, the psychologist who had been working for more than a decade with breast cancer patients. Like Oakley (1990), Noelia’s opinion was that “openness” has an enormous potential to relieve tensions both on the part of the researcher and of the researched, in particular from the researched who may feel they are being examined. Moreover, it could be the gateway to gain trust from the woman.

3.4. Whose Science? Whose knowledge? Analyzing Data and Writing from Women’s Lives²⁶

Arguably the analysis of data is a never-ending process which starts almost with the first interview itself, when I unconsciously compared the data obtained with that of the literature I had reviewed.

The laborious task of transcribing the interviews soon after I finished them was very useful in helping me become familiar with my data. It helped enormously to begin to build a picture about women’s experiences. As I transcribed, read, spell-checked, wrote comments on the interviews, as well as creating a map of the most repetitive themes, some issues became very salient. This process, quasi-parallel to the process of interviewing, showed me I was approaching the saturation point. That is to say, the point at which the information provided by my informants became repetitive.

²⁵ Shane J. Blackman (2007) similarly raises this issue in his article on “Hidden Ethnography”. He looks back on his own research situation during PhD fieldwork. In his very personal accounts about himself and his informants, Blackman seeks to illustrate how he silenced/omitted certain experiences of his ethnographic encounter for fear of failing his PhD project.

²⁶ The name of this subtitle is inspired on Susan Harding’s book: *Whose science? Whose knowledge? Thinking from women’s voices* (1991)

Initially, given that my ethnography was the first of its kind in Spain, I began my fieldwork bearing in mind “broad areas of interest” mapped out by a sense of the problem by drawing on existing Anglo-American studies. In other words, my study was exploratory and I did not assume any hypothesis. However, I must admit that finding similarities with previous research was exciting at an early stage. It felt like a sort of “passed test”, a sense that my research was going well according to the authority of knowledge on breast cancer.

However, later on during the intertwined and ongoing processes of interviewing, transcribing and analyzing the interviews, emerging findings became increasingly apparent and, to my surprise, they were quite different from those in the literature I had reviewed. Like what happened to Parr (1998: 94-97) in her process of gathering and analyzing information about mature women students returning to the education system, emerging data in my research put me in a quandary.

Despite my standpoints outlined before, I still felt confronted with the dilemma of “trying” to represent women’s voices as well as to “be acceptable to others, such as PhD examiners, journal referees, funding bodies and so on” (Edwards and Ribbens 1998b: 16). I felt that if I stretched my data I could write a thesis on Spanish women’s experiences of breast cancer based on what I call “ruling” topics (but nonetheless interesting), which include the devastating consequences of chemotherapy, the impact of breast loss on women’s body image, or, perhaps, beliefs and attitudes towards genetic testing. The other option, more coherent with my epistemological approaches, was to focus on Spanish breast cancer survivors’ and patients’ most important messages. Yet, I am aware that my interpretation of women’s voices is not completely “true” given that my academic lenses “[are] not less entangled in the workings of power” (Reyes Cruz 2008: 656).

In seeking to minimize my voice I turned to reflexivity. In doing so, I paid extra attention to women’s stories. I kept in mind Rosaldo’s questions: “what is significant in their lives, how things matter to them” (1986: 98 in Garro and Mattingly 2000: 11). What is more, I trusted the power of women’s stories to evoke in me images or to provoke visceral²⁷ feelings key to explore the experiences of women “hidden” from medicine, questionnaires, or many of the other autobiographical narratives, as I

²⁷ See Cathy Winkler and Kate Winniger’s (1994) concept “visceral inquiries” as a way of creating knowledge.

explained in Chapter 2. The need to write from women's lives is best illustrated by Arantxa, one of my informants. She neatly argued that:

There is enough stuff about women and about how we suffer with the chemo, the mastectomy and the like. That is not interesting. There are more salient issues for us women than that (Arantxa).

Although reflexivity was very important and helped me enormously to “hear” emerging themes, it did not absolve me from more dilemmas in (re)presenting data. By giving detailed accounts of how inequality is materialized and embodied in the examples of unemployment, ALND surgery, sexuality or social networks, I am aware that I have not described *all* of the factors that women mentioned as being important. Instead, I examined what I “heard” during interviews were the most important and representative aspirations highlighted by women, and in this thesis focussed on those which were quite different from the current research and policy agendas. Likewise, I am aware that by using some quotations and not others, I did not resolve the problem of women's invisibility, but reproduced it, as some women's voices remain “discriminated”, to use Couser's (1997) concept. This is not to deny women their individual experiences, or to suggest that there is no value in their particular aspirations or narrative style. However, because of limitations of space I selected those quotations which I considered better encapsulated specific examples of women's aspirations.

3.5. Getting Started: Negotiating Access

The process of obtaining data for my research was more complicated than I expected it would be, and the problem persisted throughout the data collection process.

Hammersley and Atkinson (1995: 55) argue that entry into a setting is not only a practical issue based on personal abilities, resources and physical presence in the field. Entry also entails negotiation of skills to overcome the hierarchy of knowledge.

Unlike many accounts of fieldwork which frequently mention sensitive issues as a problem for gaining access and building rapport with the informants (Wasserman and Clair 2007), I did not face any difficulty gaining my informants' trust and acceptance. My access to women was not limited by the fact that ‘breast cancer patients do not wear

a banner on their backs reading: “I am a cancer patient” which makes difficult to ‘identify’ them. It was hindered by social and medical organizations (gatekeepers or intermediaries) which seemed to be suspicious or hesitant of the legitimacy and value of my research. In the following sections I will try to make a long story short by discussing my experiences of gaining access to the field, and how they reflect the hierarchy of knowledge prevalent in my field of health research.

3.5.1. A Failure in Recruiting

In order to access women with breast cancer I used different strategies. As a starting point, before going to the field, I advertised my research on Spanish online forums on women and health. This decision was based upon my own experience as a “cybersubject” (Pitts 2004) who uses the Internet to gain information about almost-everything I want to know about. This strategy was important in my methodology, especially in light of research which draws attention to the increasingly essential role of the Internet in providing information and support to breast cancer patients (Rager 2003). Additionally, I used online snowball emails to recruit potential participants. I also used my own personal and professional networks asking them if they knew someone who had breast cancer.

Once in the field I was concerned with representing the diversity of Spanish women. I argued in Chapter 2 that the experience of breast cancer, as with any other illness, is defined by the “devastating combination” of racism, classism, heterosexism, sexism, able-bodyism, politics, culture and economy (Eisenstein 2001; Williams 2004; Hockey 1997; Standing 1997; Rapp 1993; López 1998; Mathews et al 1994). I decided to post fliers in several centres of social and community services in Zaragoza and Madrid²⁸. I made this choice because I thought that social workers would be the perfect gateway to gain access to “Other” groups of women such as *Gitanas*, immigrants, differently-abled women or women with socio-economic difficulties. To attract “alternative” people and immigrants in Zaragoza, I posted fliers in Spanish and Arabic

²⁸ Note that initially I decided to do my research in the province of Zaragoza for several reasons. First, Zaragoza is one the biggest cities in Spain and would guarantee the possibility of representing “the diversity” of Spanish women. Second, it would guarantee the anonymity of my informants. Third, AMAC-GEMA (*Asociación de Mujeres Aragonesas con Cáncer Genital y de Mama*), one of the biggest charities which works with breast cancer patients in Spain, is based in Zaragoza. Besides, the AECC has a headquarters there. Finally, Zaragoza was very close to my home. Additionally, I expanded my search to Madrid because I had to attend a summer course on “Women and Health” at the University Complutense of Madrid as a part of my fieldwork.

in diverse key meeting points particularly frequented by North Africans and *Gitanos*, such as in *La Casa de las Culturas* (The House of Cultures) and *La Casa de la Mujer* (Women's House), small groceries, hairdressers, butchers, notice boards of Internet cafés, coffee shops and phone booths. More fliers were posted in different buildings of the University of Zaragoza such as the Faculty of Medicine or the School of Social Studies. I supposed naively that they would attract young professionals enthusiastic about social research.

To my despair, I was proved wrong about the efficacy of all of these strategies as from March to July 2008 less than 10 women responded to my online adverts. No-one responded to the fliers or was referred by social services. The incentive of 30euros that one of my *Gitana* neighbours suggested did not work either.

Looking back, I think that the main pitfall of my recruitment strategy was that I had assumed that potential breast cancer patients would be active users of the Internet. However, the incidence of breast cancer in Spain affects mainly women who are over the age of 50 and Internet engagement amongst this age range is far from likely.

Furthermore, what I had not foreseen was the problematic nature of my research in the sense that I could often catch a glimpse of scepticism in the face of those with whom I discussed or presented it. But perhaps, I should not have been surprised about these attitudes (see Savage 2006). As noted before, there is the presumption that social research on health has little or no value, and probably this belief is more true in Spain. My research seemed to raise exactly the same question that Roberts' (1997b: 14) work did almost twenty years ago: "when will sociologists do something worthwhile for a change?" For example, in the majority of places I visited I could not get a personal interview with someone other than the puzzled receptionist. Other times, when I was lucky enough to meet up with a social worker I was asked to post a summary of my research outline together with credentials from the University of Sussex. Basically, I tended to be told that they "needed to think about it" (*lo tenemos que pensar*). A few other professionals seemed so excited with the project that I finally thought I had found the entry point, not to my fieldwork, as I was already facing the obstacles of the field, but to my informants. Yet, they never replied back or asked for further information.

These failures meant that another entry point had to be explored. By the end of August 2007 I had sent 53 letters directly to different organizations which worked with women, health issues, *Gitanas*, housewives, immigrants, LGBTQI and so on. I also

wrote to oncology units and to Professors in oncology. I found out their contact addresses by researching on the Internet. Of course, I did not forget to send a letter to the AECC. Replies to 10 out of 53 of the letters showed interest in my research. The AECC was not among those organizations which answered back.

Hammersley and Atkinson (2007: 55) argue that “the discovery of obstacles to access and perhaps of effective means of overcoming them, itself provides insights into the social organization of the setting”. To this day, I interpret the total lack of interest in my research as confirmation of the power of the hierarchy of medical knowledge to define health, and to appropriate any kind of expertise in the arena of health and illness. This was illustrated in one of the many emails I exchanged with an oncologist who was interested in my project. She suggested that my research was problematic because my own social approach to breast cancer challenged conventional medical thinking about health. She wrote:

Hi Ana, I received your email today. You know well that I think your research project is interesting, but I believe it will be difficult to do it here. Nevertheless, I will talk to the boss. I told you that I try to do more than medicine with my patients, I think the more open-minded we are, the more we will be able to do for them. However, I think your project is difficult to understand in my working environment. How could I say? Perhaps too open and challenging for these closed systems.

3.5.2. Renegotiating Access

In this section, I recall the odyssey I undertook to gain permission from the AECC to do the research.

I went to Spain to begin fieldwork at the end of June 2007, and by the end of July was already concerned because my strategy to recruit informants seemed to be a complete failure. By the 16th of August 2007 I had posted 31 letters to different organizations. In the letters I presented myself briefly to establish credibility (i.e. who I was, how they could find me through my Sussex online profile, and who my sponsors were); I described the project and asked for their support in recruiting breast cancer patients. I ended the letter with my contact details in case someone had further questions

to discuss. At no moment did I request access to these organizations' patients' personal details.

Among these many letters there was one addressed to the powerful Spanish Association against Cancer (AECC), Spain's leading cancer charity. I never received any answer from them which, to be honest, disappointed me given that there is not any work of the kind I am doing in Spain, and I had expected that they would be interested. It made me enquire about the context beyond the charity's key slogans: "more than 50 years working on behalf of health and prevention" or "a joint effort oriented to be more efficient and effective to detect the needs and priorities of action". Perhaps my project was not seen sufficiently as a call for action because I was not interested in the disease but on women themselves and the social contexts of their illness (see Scheper-Hughes 1979: 13).

Almost a month later, on the 10th of September 2007, I decided to try my luck again by sending 23 more letters to different organizations. One of these letters was addressed to the Women's Department of Carolina's Council who referred my letter to the AECC headquarters in Carolina. AECC Carolina emailed me welcoming my research several weeks after that. Finally, on the 18th of December, we agreed that I would start my first interviews the second week of January. Despite the fact that I had to move a long way away, Carolina being almost on the other side of the country, my happiness could not be tarnished. Or that is what I thought. Two days later I accidentally received a very unsympathetic email from the central AECC office postponing the interviews. Note that the central AECC office did not reply to my letter almost five months previously.

The meaning of time here deserves a PhD thesis of its own. The process of getting into the field and finding informants seemed to me infinitely slow and frustrating. I felt helpless because I did not have any control over the situation: calendar months passed very fast yet I did not have any informants nor did I have any sort of institutional support in Spain. With this new email, getting *into* the field seemed not just a huge but an impossible enterprise.

Not only was I struck by the tone of the email, but I was surprised by some implicit statements. The fact that the email was only for internal use but came accidentally to my inbox did not lessen my feelings of annoyance. I felt the tone of the email was demeaning and patronizing. More even if one takes into account the fact that they had ignored my first letter. It sounded as if they were exasperated by the insistence of my

insignificant project. That particular day I remember I interpreted the email like a sort of boycott. First, whenever they referred to me they used “that person” instead of using my first name and surnames (in spite of the verifiable personal information I had given), formulae which sounds offensive and demeaning in Spanish language.

Second, they were asking for a signed consent form “where I must explain clearly the basis of the project and the negative consequences”. Fair enough. But it reflected that they did not have much knowledge on what social science research is about: the professionalism, the protocols, the procedures and the rigorous Anglo-American concern with protecting informants. Besides, in my presentation letter I had made it clear that prior to the interviews I would explain the aim of my research followed by a written consent form. My PhD proposal was demeaned in such a way that they made it sound like a school project.

I was tempted to send back an email drawing attention to the fact the medical establishment in Spain have massive problems when it comes to consent. Of course, I knew quite well that often cancer patients have a very short period of time to read and, literally sign, very technical long consent forms about their treatments. Pressing time, the impact of diagnosis, and technical language often means that patients do not assimilate the content of the consent form. This impedes them from asking more questions or demanding active participation in therapeutic choices. Besides not all consent forms are fully informative. There are many (serious) symptoms which are overlooked (see Rosser 2000), for example when it comes to information on sexuality or on the implications of armpit surgery on women’s wellbeing, as my fieldwork turned out to reveal poignantly. I will turn to this point in Chapter 6.

Third, in my concern to establish credibility I wrote down that my research proposal statement on ethics was approved by the University of Sussex. A prerequisite of the AECC was that my research proposal had to be tested again. Fair enough. I perfectly understood and, indeed, I expected this to be the case. But again, the tone of the email provoked me because I remember vividly that before conducting my Master’s fieldwork I asked several Spanish professors about whether my research proposal had to be approved by an ethics committee in the country. I was told that it seemed that no one had heard anything about any ethics committee for social research on health. Moreover, it seemed that the AECC itself had not heard about it until my statement fuelled its ego.

Fourth, I could sense a sort of accusation that I was asking for patients' personal details, which was not the case. Again, this revealed their lack of attention because they had not read my letter in detail, let alone asks me for further clarifications.

And finally, I found the impersonal manner in which they did not communicate directly with me but through AECC Carolina very disdainful. I think it would have been as simple and efficient to send a (polite) email or phone call explaining personally their requirements before granting me with research permission. Additionally they stressed that they must appear as collaborators in all the publications resulting from my fieldwork.

To sum up, these were the reasonable main issues presented as prerequisites before granting me permission: I had to send my research proposal translated into Spanish; credentials from Sussex University proving that my proposal was approved; the interview questions; and the consent form. For a while I was doubtful of doing the interviews in Carolina, I thought it would place me in a difficult position in terms of not being able to reflect critically upon my research journey. But my supervisors encouraged me to face the challenge.

Once I relaxed, I wrote a diplomatic email "apologizing for any possible lack of clarity which could have offended the integrity of the association". I assured them that I would post all the documents by the next day. My email seemed to have smoothed things over. This same day I was asked politely to send all the documents to the central AECC office, but I was warned that they would not be reviewed until after Christmas. That meant that I could not start the interviews as we had arranged, instead I would have to wait for at least a month more.

On the 17th of January, the central AECC office sent AECC Carolina an email stating that they had reviewed my documents, but had found that my consent form was poorly constructed. They gave me some recommendations on how to improve it in order to get the go ahead. Regarding the ethics committee, they were not yet sure whether my proposal had to pass a committee of ethics or not. They had to find out so I was asked to wait a bit longer.

Finally, on the 7th of February I got the green light to start my research on the 18th of February. In the meantime, I was asked to send all the information to Carolina Hospital. Apparently the hospital was the body ultimately responsible to grant official permission for me to start my research.

I prepared my luggage to go to Carolina with excitement. During those months I had the chance to interact via email or the telephone with incredibly kind and supportive people there. They had worked very hard in order to start off the proceedings that would make my research a reality.

My first day at AECC Carolina was very memorable. Pedro, the coordinator and the psychologist Noelia, took me around the association, proudly introduced me to any person who happened to be there at the time, and provided me with lots of information and different leaflets edited by the association. I was glad that I sent that diplomatic email. My stay in Carolina was smooth and fruitful.

However, later on the biomedical dominance characteristic of my field would restrict my access to data. For example, I was denied permission to travel in the ambulance to the radiotherapy sessions by a powerful member of the staff of the AECC Carolina. My wish to explore the radiation journey was moved by my professional curiosity, but also by my commitment to bring women's demands to the fore. As briefly mentioned in Chapter 1, cancer patients who live in the province of Carolina do not have the facilities to receive radiotherapy. If they are to be radiated they would have to travel by ambulance to the closest hospital available provided with a radiotherapy unit. Imagine the scene of a cancer patient who has to travel daily up to 350km one way for just 3 minutes of radiation treatment. Because the ambulance takes on board other patients from Carolina or surrounding towns, women cannot return home straight after they finish their session, they have to wait until the last patient has received their treatment. But more annoyances arise when they discover that each patient has very different timing for their appointments. For example some patients may have to start at 11am for which the journey starts at 7am to be on time, but the last patient may have their treatment at 4 or 5pm. This means that they arrive home as late as 8 or 9pm. Many women described these journeys as unbearably tiresome. According to my informants and some professionals I interviewed, this situation of abandon and discrimination of cancer patients in Carolina is "deplorable" (*lamentable*).

When I asked if I could accompany them, I received a frustrating categorical 'no' as an answer. I was told I could not go into the ambulance because officially I was not a volunteer of the AECC. From women's accounts I knew that patients could choose to take an accompanying person with them in the ambulance. As I wanted to show my respect to the AECC I did not ask directly to my informants if they would allow me to

go with them to the radiotherapy sessions. This reminded of my precarious position as outsider, yet I had to acknowledge the AECC as a collaborator in all my publications and presentations. I thought: what kind of deal was this? Was I the only swindled anthropologist in the history of anthropology?

It is only fair to conclude this section acknowledging that in spite of many problems a few individuals of the AECC posed to me in carrying out my research, it also fuelled my intellectual stimulation, resulting in this section. Besides, I have to thank it for introducing me to the women of this study in addition to the special world of the AECC. I am deeply appreciative for its support in the latest stages of my research when it recommended me to the AECC in Zaragoza so that I could conclude my fieldwork nearer to home.

3.6. On Shame: A Journey of Discovery of My Class Unconsciousness

This section explores my social class (un)consciousness shaped by my biography, and how in “the journey of discovery of this thesis” (Richardson 1994 in Shivdas 2003) I learnt why the concept is, and should be, relevant for this research. Initially, despite the advice of my supervisors, I was at first reluctant to acknowledge the importance of class to my research. It seemed to me an aberration that the social care system and the NHS were classist when its founding principles are meeting the needs of everyone, providing free healthcare at the point of delivery, and assistance based on clinical need not ability to pay.

However, my findings, and other literature I am now familiar with, show that class is always present and permeates all spheres of women’s lives, and dictated women’s employability even more noticeably after breast cancer. My ignorance of class in Spanish society was in part because I did not identify the Spanish class structure with the British one, as I will now explain. Only by unravelling first my own experiences of class can I explain my classist lenses and, by becoming aware of them, how I came to understand the importance of integrating a class analysis into my own research.

My sister, brother and I were brought up by working class parents in a small village. My parents grew up during the post war (1950s) and my grandparents were farmers. My mother’s ambition for a career was constrained by her responsibilities to bring money

home, and later for her responsibilities as mother and wife. My father was more fortunate than my mother, and than many of Spaniards of his age. Because he was a brilliant student he was offered a place in the one of the top educational institutions of the time in Zaragoza. After several years where he earned his qualifications he decided to quit in order to start a course on automotive engineering. After he finished his course he worked several years in the city, first as an apprentice and then as a mechanic in “his own right”. These experiences prepared him to start his own business with one of his brothers in the village.

My mother still retells me of her feelings of anxiety when my father told her he wanted a garage of his own in the village. She explains that they did not have money at all when they married and for many years to come. Indeed, their income was almost only of subsistence: they were renting a house as well as my father’s garage, and my sister and I were still only babies, making it difficult for my mother to work outside the home. Yet, not working was not a choice for my parents, and my mother had to work in the textile industry from home. Nevertheless, they decided to go ahead with my father’s project. They mortgaged not only their savings, because they did not have anything at all, but their lives in order to build my father’s garage and my parents’ flat.

To these days I still think of my mother as a Bank Manager. I admire her ability to stretch and juggle my father’s wage to the point of being able to pay back the mortgage and sponsor our degrees and my brother’s education. Indeed, it amazes me how my *working class parents* were able to help me so much financially with the expenses of my MA and PhD in the UK.

In the reflexive exercise of writing these lines about class and my biography, I think again of my village, the villagers and friends, and my family there as well as my colleagues at the Universities of Zaragoza and Barcelona where I did my degrees, and I am not able to find those markers of class that are so obvious in the British society. Indeed, although Spain is *very* classist (I am *very* aware of it now), I still believe class hierarchies are not as tangible as in the United Kingdom, a country which I know well having lived here for the last seven years. I must confess that I was horrified when I arrived for the first time in the UK, more specifically to Bradford, where I could see the ubiquity, tangibility and social disgrace or stigma of class. Class is present every day in the British media. There are countless examples of negative references to the working class. Indeed, the working class is constantly ridiculed for its taste, manners, accent, and

failure to accomplish the ideal of “Englishman”. The working class is also to be blamed for a big part of the miseries of the country: increase of violence, drinking, ruining the image of England abroad, abuse of taxpayers’ confidence, high levels of teenage pregnancy, unemployment as a livelihood, and so on and so forth (see for example Tyler 2008; Nicholas and Appleyard 2008). These images stood in sharp contrast with my own reality as a working class woman who had the possibility to enter high and university education.

With this tragic picture of the class system in Britain in my mind, and short-sighted as a consequence of my “classist lenses”, reinforced my misconception that my own country was not classist, and that it was more egalitarian than the UK. It seemed to me an aberration that someone could be discriminated against, be regarded as inferior or “uncivilized” on the basis of class, when all my good friends and loved ones are bright, intelligent, educated and hard working, especially when I have the example of my father as one of the most intelligent and cultured persons I have come across in my 30 years in the education system. Besides, my parents educated us in the principle that knowledge (*el conocimiento*) is more important than money, material things or expensive holidays. My father’s philosophy “I am the richest even though I am the poorest” sums up well my “idea” that class did not matter since I thought that class was *only* related to financial position. Nevertheless, I still do not understand why it has taken most of my life to understand that his predicament was an ideological statement about class.

In reading Vicenç Navarro (2006) I recognize my misconceptions and classist lenses. As I said, I was unaware that I was educated in “thinking class”. In fact, my parents’ principles about gaining knowledge (*conocimiento*) were another way of defining class in a way which is not associated with financial status or occupation.

As some may argue my classist lenses were not because “I have never wanted not to be working class or to ‘get away from it’ or ‘escape’ as is commonly assumed about working class people” (Steedman 1986; Skeggs 1997 in Zmroczek 1999: 92). It was because somehow I had the mistaken picture in mind that class was something remote from my life. If I ever thought of my social circumstances, I thought of myself as a “normal”, “average” citizen who has to work for a living as most of the citizens in Spain do. However, in doing so I was ignoring the fact that there are many “normal” citizens for whom work is not a choice and for whom deprivation is the norm. Naively I did not question myself as to whether “there are political, economic and social forces that help

to produce inequality” (Kerbo 1991: 9), rather I took inequality for granted as if it was caused by personal misfortunes.

As indicated by Navarro (2006: 29), and by my own experience, taking class for granted seems to be the norm in Spain. He points out one major obstacle that invisibilizes the pressing reality of class in Spain. The obstacle is that the working class has changed its composition, switching from manual sectors to the service sector (see also Marks and Baldry 2009) and now has access to more commodities (e.g. consumption). This means a change in status attached to occupation and an increase in the gross domestic product per capita. However, Navarro (2006: 29) points out that this does not make the structure of classes disappear for what defines the social position of citizens is not as much the living style but the social distance between collectives²⁹.

Returning to the main issue of this section, the question of class *in Spain* started to gradually take meaning for me during my research and how this *does* affect women’s experiences of breast cancer. All of a sudden, I came to understand that the economic position is but one criterion to distinguish class, and that *even in Spain* “they way people live, get ill and die depends a great deal of how they are positioned in the social structure” (Navarro 2006: 29).

On reflection, I understood too “that class construction must be viewed in specific cultural contexts” (Lentin 1999: 29; see also Brenner, 2000; Franklin, 1999; Hawthorne 1999). In other words, I realized I cannot write about my informants’ class position in isolation from the variables such as women’s agency, gender and age, nor I can avoid mentioning the influences of personal trajectories, social networks or the Francoist regime which shaped in part many of my older informants’ class position in terms of occupational skills, for example, by defining women’s role at home, thus restricting their access to education and the labour market. I will explore this issue more in detail in Chapter 4.

By interviewing women I realized how important class is in affecting how women navigate the violent storms of inequality triggered by breast cancer. Many women had to confront the inequality of class when they were threatened with the poverty of

²⁹ In line with Navarro, the sociologist Annandale stresses that: “the process of social polarization is partly hidden by misleading ‘average’ improvements in standards of living which conceal wide variations, and the fact that while the conditions of the well off have got even better, those of the poor have changed very little, and may even have deteriorated (Annandale (1999):90).

unemployment because the disabling effects of breast cancer impeded them from returning to their jobs, or because it demanded sickness leaves. Class would exacerbate the inequality of those already more vulnerable women such as women from lower social classes, women who were widows or divorced, had dependents, or were the main breadwinner. Serious economic strains as a consequence of unemployment or sickness leaves were the source of tremendous anxiety, which had the potential to seriously disrupt family functioning and burn out social relationships, affecting in turn their psychological and physical health. Class also impacted on women's access to "luxury" CAM and leisure.

Although I have only incidental data on this, I suggest that "cultural capital" (Bourdieu 1984) or "class as culture" (Bettie 2003) was very important not in women's access to medical care but to the quality of care they received, as I will briefly explore in Chapter 6.

3.7. Conclusion

In this chapter I have outlined my standpoint as that of feminist critical ethnographer. Such a position demands a political approach which aims to empower those who are being studied. I have explained how political narratives of breast cancer are invaluable not only because they empower women because the act of telling stories can be healing and liberatory, but because they are revolutionary in the sense that they theorize from experience (hooks 1994: 61). In other words, women's stories open a window to "the gritty realities of social structure and social change from a particular position and point of view" (Williams 2004: 279). I have stressed the need of listening empathetically to women's voices as producers of knowledge and the ethical dilemmas that this poses in terms of bias, objectivity and validity. I have described the odyssey of researching a medical topic from a feminist social point of view in Spain and the process of (re)negotiating access to the field. Finally, I have reflexively outlined how my research *cried out* for the need to incorporate an analysis of class and how I came to terms with my class unconsciousness.

Chapter 4

Social Inequality and Breast Cancer: The Example of Unemployment

4.1. Introduction

Early on in my fieldwork I came across an unmarried woman in her sixties called Andrea. Andrea was a breast cancer survivor full of energy who had survived the precariousness and vicissitudes of the late post-war era by migrating from a rural village to a big city like Barcelona. She had also survived three battles with invasive cancers.

Andrea entered higher education as a mature student and forged herself a career as a nurse. In 1994, at the age of fifty, she found herself “all of a sudden” (*de pronto*) diagnosed with breast cancer and “left in the street” (*dejada en la calle*). Right from the beginning of her account she explained that the hospital where she was working was undergoing some cutbacks in the workforce, and, assuming she would take more sick leave as a consequence of cancer, fired her from her job. Despite Andrea’s qualifications, experience, and determination to work, she told me that she encountered many difficulties when trying to go back to work. I asked her how she survived without working and she explained that she managed to counter the discrimination she experienced in the labour market, mainly on the basis of her age, because she was pro-active in searching for a job, and because she made use of her wide network of friends, acquaintances and colleagues in the health and care sectors. Besides, although she was a qualified nurse, she accepted to take any unskilled job which was on offer.

Four years later Andrea had an aggressive recurrence and doctors did not give her any hope of recovery. Due to the demands and hardships of her treatments which had weakened her body permanently, she was forced to leave her job definitively. At this point, she and her doctors decided that she should apply for disability benefits. Fortunately, she recalls, her application was accepted.

When talking about her breast cancer experience, first on the telephone to arrange an interview and later face to face, it became clear that the issue of (un)employment had

negatively marked Andrea's experiences of cancer. Indeed, she was very aware of the precariousness of her own situation in the labour market. She made a very close connection between her age and the job discrimination she encountered. Nonetheless, she was also aware of her privileged status within the hierarchy of class and knowledge granted by her qualifications as a nurse:

You know, being 50 and without any options... although my CV was really good, because I was 50 nobody wanted [to hire] me. Yet, I was very lucky because I had many contacts. I worked as care worker, then I did some other temporary jobs until I had the big recurrence and I had to leave my job. It was as if I were disabled. As if I were unable to do the sort of things I had done before, there are certain things that we can't do, but we are able to do most of them.

Unfortunately for Andrea, she not only had an illness like cancer, which is associated with extended work absences and ultimately death (Sontag 1991), but more importantly, she also belonged to the social group of older workers "popularly associated with a declining capacity to work" (Laczko and Phillipson 1990: 89). All in all, Andrea was in a more advantageous position than the majority of Spanish women (living with breast cancer) of her age as this chapter aims to illustrate. Andrea was single, she was not responsible for any dependent children nor relatives, and, more importantly than anything else, she was qualified and had been employed most of her adult life. This had provided her with an invaluable financial independence, in addition to a wide social network which had helped her to navigate the challenging task of looking for a job at the age of 50.

Andrea's story was the story of a social injustice: of a fight between a breast cancer patient and an *illness*. A fight against not only cancer cells but also structural violence. I shall tell the oft-repeated story of this fight in more detail in this chapter.

4.2. Breast Cancer is Inequality: Embodied and Materialized

It would be difficult to exaggerate the harms caused by breast cancer throughout the process from diagnosis to treatment, and back again to "normal" life. Breast cancer is many things, all of them bad. It is a life threat and a fear. It is a diseased body, an alien

body, and pain. It is lack of control and dignity. It is exposure to emotional insecurity and material deprivation. It is inequality embodied and materialized. This chapter seeks to provide a new approach to the question: why does breast cancer matter? Let me expand the question and ask what differential impacts breast cancer has on Spanish women, and illustrate why social inequality in breast cancer experience exists, and why it needs to be reduced. In listening to women's narratives of resistance we can see how social inequality becomes expressed and embodied in their experiences of breast cancer. Making these dimensions explicit can have radical implications for breast cancer policy and care.

Often research on inequality in health is conceptualised in economic terms, for instance analysing the level of investment in health services (see Navarro 2006). However, this focus neglects two important facts. Firstly, economic analysis of health care *provision* fails to see the economic *impacts* disease has on disease sufferers, for instance, how it affects their household income and expenditure (see Durán 2003). Second, it fails to analyse how the economic impacts of disease are affected by geographical location and other axes of social difference, and associated inequality, such as gender, age, and social class. It is this latter point that I wish to explore in this chapter. I am not interested so much in quantifying the huge economic impacts of breast cancer on women's experiences, but am more concerned with understanding the ways in which major structural forces produce and reproduce *social* inequality in breast cancer experiences, which ties in with, reinforces, and exacerbates, economic inequality. Thus, recognition of the implications of social forces such as age, gender or social class, as well as attention to how other intervening factors such as geographical location and access to resources and the quality of social networks, are as important as quantifying the economic impacts of breast cancer in giving us a deeper insight into understanding how breast cancer patients in Spain navigate their illness.

As I talked to women I realized how little I knew about how Spanish women manage their lives following breast cancer, how breast cancer jeopardizes their ability to engage in paid work. Most women described how cancer threatened their jobs in one way or another in form of employment discrimination, disability, unfair workplace or unfair policies (Davey, Austoker and Macleod 1999). Some women described their move from employment to sick absences to unemployment or, if they were lucky enough to be believed by biomedicine, to the legitimate status of "permanently

disabled”. Women gradually led me to appreciate three important interactions between breast cancer and social axes of difference (and associated inequality) which are often absent from public discourses. The first is that breast cancer predominantly affects older women (e.g. women aged 50 and over). Although this is manifest in my sample, as well as in national statistics of breast cancer shown in Chapter 1, media and public discourses tend to portray a very different picture of women with breast cancer³⁰, one in which the cancer patient is a young and beautiful one, and probably wealthy. Thus, the impact of Spanish society’s ageism on breast cancer patients is often ignored.

The second point is that although Spain has one of the best free and universal health systems in the world and a National Plan Against Cancer (ECSNS), these *do not* guarantee all women access to the best quality of care and resources available in the country, and this difference in access cross-cuts with social class. Again, this fact is invisibilised in current research on breast cancer experience.

The third point is that breast cancer patients *do* work, including within the cash labour market. Indeed, 17 of my informants were active employees, and in agreement with the literature reviewed in Chapter 2, paid work among this group was often not a choice but an urgency (Doyal 1995: 152), necessitated by their social and personal trajectories. Certainly there has been a growing number of women participating in the labour market in Spain since the 1980s³¹ (Santolaria, Fernández and Daponte 2004: 25), which means that breast cancer will increasingly affect more and more women who are engaged in paid work. The fact that breast cancer patients work in the paid labour sector, and that this sector is fundamentally discriminatory on a gender basis, is, again, ignored in literature on breast cancer experience. This chapter builds on, and returns to,

³⁰ Like in the UK (Saywell, Beattie and Henderson 2000) or Australia (McKay and Bonner 1999), the Spanish media and public reports (e.g. from the AECC) project an image of a young breast cancer patient. For example, a quick search on Google evidences that there is a tendency to show “heroic cases”, to use Clive Seale’s concept (2002), of famous breast cancer patients or survivors who are young, like singers Kylie Minogue, Sheryl Crow, Anastasia, or Chambao’s singer La Mari. An important institution in the fight against cancer, the AECC, often invites celebrities, especially young women, to back up its awareness campaigns. The last 2010 campaign included celebrities Lolita Flores, Olivia Molina, María de Castro, José Toledo y Almudena Cid (see MujerHoy.com 2010 online).

³¹ It was only in the mid ‘80s when Spanish women started entering the labour market in significant numbers. For example, in 1975 the employment rate of women was 27 per cent compared with 49,2 per cent in 2007 (Varela 2008: 223). In contrast, large numbers of British women entered the labour market a decade earlier, for instance in 1971 the employment rates were double those in Spain, at 56 per cent. In 2008, the employment rate of British women was of 70 per cent (Office for National Statistics 2009: 1). This example shows that context is a must when we attempt to compare experiences of breast cancer patients and unemployment across countries.

these three “realizations”. They are of direct relevance to understanding how social difference and inequality affects women’s experience of breast cancer in contemporary Spain, yet have been ignored up until this point.

In the next part of the chapter, I turn to the individual lives of two women, Che and Amalia, because they provide particularly telling examples of the situation that is of interest to this chapter: the complex and unequal nature of cancer experience. Where possible, I have tried to do this in the words of the two women themselves as I feel that their testimonies are powerfully expressive. These examples illustrate best how a biological disease like breast cancer has far-reaching social, emotional, and financial consequences for women and their families. It shows that when social institutions, organized around axes of social difference, such as gender and age, are violently combined with women’s personal trajectories, they can have serious effects on women’s employability, increasing their vulnerability to, for example, emotional distress, access to resources and poverty. By focusing on the impacts of breast cancer on women’s (un)employability, I attempt to show the linkages between social differentiation, economic status, and breast cancer. The case of breast cancer patients’ differential access to financial resources, either through work in the paid labour market or through the social care system, is an arena in which the multiple, yet interlinked, effects of social inequality due to ageism and sexism are readily evident. It elucidates the complexities of these women’s social and personal trajectories, and their current situation.

My overall argument is that breast cancer is an example of the inverse care law, where social inequality operates, is nurtured and is (re)produced (see Girad 1977 and Taussig 1987 in Escobar 1995: 214), sometimes violently, sometimes subtly, having a huge impact on women’s lives, especially among those women who are more vulnerable (e.g. women from lower social classes, older women, divorced women). So, this chapter offers a new perspective on the ways breast cancer (re)produces social inequality.

4.3. Che’s Story

Che represents one of the many hidden faces of breast cancer which I attempt to uncover in this thesis - one in which women are not able to afford sick leave, not only because they are the family’s breadwinners, but because the sword of Damocles hangs

over their employment. Far more disturbing, as in the case of Che, is that the immediacy of cancer presents a grim fate for those who are self-employed and who invest more of their lives and savings in their businesses.

I met Che at the AECC. Noelia, the psychologist of the AECC in Carolina, had suggested her name on a day when I was discussing my findings about the impact of cancer on women's employability with her. Noelia arranged the interview for me and encouraged Che to participate in my study. She accepted right away. Literally she explained that she would like her financial, professional and family difficulties to be heard by politicians and society in general. She "aspired" (Appadurai 2004) that her experience could contribute to changing attitudes and influencing fairer social policies tailored according to each "local world of suffering" (Kleinman 1992). The difficulties of a cancer patient, Che explained at the beginning of the interview, not only had to do with the illness, as most people think, but also had to do with all the "several additional problems" unleashed by cancer.

Before the interview, Noelia warned me about the roller-coaster of emotions which had swallowed Che up and could overwhelm both my data and my emotional well-being³². Indeed, I immediately noticed Che's anger, pain and disappointment, and could relate to Sered and Fernandopulle's (2005: 24) words: "so tangible, that, inured to emotion as we were after conducting dozens of interviews, we soon shared her fears and felt ourselves engulfed in her pain".

Che was relatively new to the AECC. She had heard through some of her clients at her job in a hair-salon that the AECC provided free individual psychotherapy. She told me that her clients were very grateful to Noelia who had helped her after she decided to seek help right after the breast surgery when she realized that "the rage, powerlessness, lamentations, palpitations and anxiety" started dominating her life.

Che was 45 and had owned her own hair salon in the city of Carolina for almost 15 years and had two employees. Che loved her job and loved talking to her clients. For her, her job was art and allowed her emotional relief as well as financial independence. She was married to a man who had been unemployed for a long time, and who did not provide her with much emotional support either. They had a six year old son together.

³² I guess that Noelia wanted to forewarn me about the high risks of getting "contaminated" or "non-objective" data given the volatile nature of Che's mood swings. One the one hand, Che was experiencing *ataxia* or lack of coordination as a consequence of the first effects of her first round of chemotherapy. One the other hand, at times Che's narratives could become very agitated and tempered as she tried to disentangle the unfairness of her chaotic life.

After working for more than 10 years in someone else's business, Che quit to open her own hair salon with the help of a loan and the investment of uncountable working hours. As is the practice for hairdressers in Spain, Che worked for a minimum of 9 hours daily, not including those hours spent on other administrative matters:

The problem is that the girls (her employees) haven't got supplies, pay slips, quarterly payments, letters from the Inland Revenue...you didn't know that I woke up at 6.30am this morning in order to prepare some documents to go to the *gestoria* (agency).

Because of the hardships and demands of starting a hairdressing business from scratch, the couple delayed having children. When the business was relatively well-established in the county, they decided it was the right time to have a baby. By that time Che was 39.

Given that she had won a reputation as a stylist among her clients, they foresaw that her business could be badly affected by a maternity leave (she explained that most clients prefer the stylist and not the trainees). It became clear for Che and her husband that he would have to take the paternity leave. According to Che, this would negatively mark her relationship and her subsequent experience of her illness. A week before the paternity leave was due, her husband was told by his employer, "without any apparent reason, that his services were not needed anymore". As far as Che was concerned, her husband was fired because he applied for paternity leave³³. Her husband then suffered from depression and had been unable to secure permanent employment ever since. This vicious cycle further worsened his mental health problems making it even more difficult for him to find any sort of temporary job.

Over the course of the conversation, Che explained at length about the stress of living with a man who was gloomy, depressed, apathetic, and who did not support her economically or emotionally throughout her experience with cancer. Above all, she spoke about the constant worry of not being able to afford to get sick and how this:

³³ Although Paternity Leave is legal in Spain, taking it up is still extremely rare. In 2003 only 3,6 per cent of men took Statutory Paternity Leave (Instituto de la Mujer 2003 in Peterson 2007: 43). The dismissal of Che's husband reflects patriarchal attitudes which stigmatize and punish those men who do not conform to expected gender behaviours.

Corrodes me tremendously, bitterly and viscerally. Ever since, he has become an unbalanced person. They didn't respect one of his rights. They fired him. And we suffer from it since that moment. How can a balance exist if the strong person in the couple gets sick now?

Like many other breast cancer patients, especially, those who are older, widowed, divorced, single mothers, or belong to the lower classes, Che could not contemplate quitting her work in order to allow herself the time to fight and recover from the illness. She was haunted by the responsibility of being the only breadwinner at home. She explained:

In a situation like this, one of my colleagues closed her business. It is O.K. if you can afford to quit, but the thing is that each person has a different situation. I told a colleague from a nearby city 'your shoelaces are well tied, but I am just starting to tie my own laces'.

Or, as things were unfolding for Che, her shoelaces were starting to tragically unravel. The directly negative impacts of getting sick were many. First, Che knew well that every day that passed without her working at the salon, she lost more clients because her employees could not perform at the same level as her:

They can't do as much work as I can. I am especially worried about the Easter Campaign. I have some brides who are asking me already "will you be back by then? If not we will look for another hairdresser". The owner is not the same as the employee.

I wondered about her regular clients and she answered straight away "today not even your husband is loyal".

Second, without work there was no income to pay bills, employees or buy food. When I met Che she had only had one chemotherapy cycle. She could not receive her second round because her immune defences were too low to resist a new dose. She attributed this to her stress as much as to the effect of chemotherapy on her immune

system. Che did not dread cancer itself, she dreaded the treatments and how they would affect her body, her mind, and her ability to work again:

I understand that the cancer is eradicated after the surgery. But now, I am so afraid of the treatment. Because I don't know how much it will deteriorate my immune system. But I don't have any option. I can't forget about my business even though I *want* to. No matter how many times the psychologist tells me to forget about it, it is still *my* problem. If they told me that I would be going to earn monthly the same amount I used to earn as a hairdresser I would be relieved from many problems.

As I consulted Noelia, and a close friend who works as an advisor in a very prestigious trade union, and hear from women, I learned that self-employed workers in Spain do not have a right to claim unemployment benefits. Until recently they did not even have a right to sickness benefits from the state, which is still currently very modest. In addition, they have to pay the Inland Revenue quarterly payments regardless of whether they are ill or do not get any work done. They are not entitled to paid holiday either. The vulnerability of self-employed patients was summarized bluntly by Che:

The Inland Revenue doesn't give a damn if you have to close your business. Because if you are the owner and you are sick, it is your problem... It makes everything difficult and doesn't allow you to be ill.

Given the hardship of the social care system for self-employed people in Spain, many decide to pay for private health insurance as a complement. But often, it is easy for insurance companies to deny compensation claims by arguing that diseases such as cancer were not covered by the contract. Delays and unfulfilled payments are also common (see Sered and Fernandopulle 2005). Che recalled an incident with her private insurance company some weeks ago before the interview:

As I am self-employed, I want to receive my sick benefits from the first day I am ill. Thus I have a private insurance. I found out that they will pay me at the end of the treatment because it is going to be a long sick leave. I asked them 'right,

do I not have to eat every day? It (the money) comes from heaven'. I wrote them a letter asking if I could have an advance It is that I see myself... I see myself thrown away as a butt (*colilla*). I feel this way even more because my husband doesn't have stability in his job. His contract finishes in 15 da. And I am told: "God only puts us to the test when He knows we can do our best". Yeah, but He guides some of us to the guillotine!

This incident made Che's world fall apart. Che had worked really hard to keep her business afloat; she managed to meet the Inland Revenue's harsh requirements and the private insurance payments; she had sacrificed her dreams of having a big family; she had even sacrificed her relationship; and having gone through all that, she felt she deserved "the right to be ill" (*derecho a estar enferma*). Movingly she said:

If they said 'Dear patient, we are going to give what you have earned. Because you deserve it, because you have been paying for all of these years. So we believe you deserve it for a year'. Because I do believe I deserve it. I've been working for 15 years self-employed and I always paid the administration what they asked of me. I never withheld anything. Even when I had inspections, they could never find anything wrong because everything was legal.

To add more to the stress of her situation, one of her employees decided to quit:

All of a sudden she realizes she is not made to be a hairdresser. And I thought of her: 'of course, I always hid your defects and now that I am not there, they can be seen. And you don't have much tact to for dealing with difficult clients'. So I have this other problem now. I have to look for a substitute. I told her 'I understand your situation. I don't want you to work unwillingly'. On top of that I grin and bear it and tell her these things when I am thinking inside 'please, don't quit immediately, please. At least, let me find someone. Someone useful who doesn't finish by ruining everything'.

In a sad irony, Che's husband got fired when they decided to protect and benefit Che's business because she was bringing more money home. Now, she lacked both the economic stability of her business and her husband's support:

Things have gotten worse since the diagnosis and he complains that I have many visitors at home, [and this] is disrupting his life, of course. He also accuses me of not doing anything at home. But this time I really need someone to take care of me. I decided I had to move to my parents' and that he would take care of our son. I have much bigger problems than the illness itself, so at least in what concerns the house I can be relaxed. I can guarantee you that I won't have been able to come to this interview otherwise.

Che was aware that she needed "peace" (*paz*) to "boost her immune system" in order to go back to work as soon as possible to keep her business afloat and bring income home. But more problems arose precisely because she felt guilty about "leaving" her son. According to Noelia, although it was also obvious during the interview, this decision was a traumatic one for Che.

To make things worse, Che told me that many neighbours and acquaintances in Carolina judged her decision as being an abandonment of her son. She was aware that she was transgressing the norms of "good" motherhood and she blamed herself for being selfish, but she saw this as the only way out to recovery. Without hesitation, as someone who has consciously thought about the alternatives, and decided that there is no 'good' option but rather a bad one and a less bad one, she said: "if I die my son will lose his mother". I will return to this point in the next chapter.

As we see, for small businesses like Che's, fortunes can easily take a downward turn with just a cancer diagnosis. She started her small business from scratch but managed to succeed in her career. She bought a house, paid off the loan for her business, and hired two employees. During this time Che prepared herself "for the future": she saved money and paid additional private insurance. However, although Che may be able to fight her illness and all payments, the scenario of her future is a frightening one. The reality is that Che is employed in an occupation which is particularly badly affected by armpit surgery. So, at the age of 45 she is left as the only breadwinner with a

husband and a child, but it is very likely she will not be able to work again in the only job she is qualified for.

4.4. The Story of Amalia

In spoken Spanish, when we want to convey that the life of someone is complicatedly tragic we say ironically that “his/her life is a poem”. Certainly, the life of Amalia was a poem. Her life experiences far exceeded the impossibilities of fiction. For her, life was never fair, whatever this means. Yet, she did not portray herself as a victim but as a survivor of an accumulation of “extremely painful” events in her life from which she tried to come to terms by looking forward to a more serene future “without always looking back at the past”. To understand Amalia’s struggle against cancer we need to untangle her past life experiences. This is best indicated by an apologetic comment Amalia made about herself talking more about her past than about her illness, about which she was being interviewed:

Well, it has happened that, I am talking more about my problems with, well, but it is that it all happened simultaneously. I think one thing triggered another thing. Everything goes together, and you cannot separate them because everything goes at once.

Amalia came to seek help at the AECC when she started undergoing chemotherapy treatment about ten years previously. She had not stopped coming ever since because the AECC provided her with a space to keep her mind busy and away from her financial and emotional problems. Despite the fact that she was married and had three grown-up children aged 21, 19 and 17, she felt utterly lonely in her battle against cancer. Like Che, she did not fear the illness. She feared the loneliness of her home, the destructive nature of the relationship with her husband which marked the experience of breast cancer, and the effects of cancer treatments on her ability to work.

When Amalia was 25 years old her 50-year old mother was diagnosed with a disabling illness and decided to end her own life. According to Amalia, her mother’s death would tragically mark her own life forever as things would later unfold. After the death of her mother:

I ended up being responsible for my three small children, my father, my sister who was 11, and two houses to attend to. That time I had no time for myself, or for any problems, or absolutely anything else. And I think it did harm to my marriage.

As Amalia anticipated, things did not work very well in her marriage from the very beginning. She explains that this was not only because she was really busy with caring for her immediate family, but because her husband was very prone to invest, spend money, or make important decisions without consulting her. Amalia could only suspect of her husband's increasing debts whenever letters from banks arrived. By the time her youngest children started secondary school it was obvious that they had serious financial problems. Consequently, she had to start working as a kitchen porter in a restaurant from 10am to 18 pm in order to secure their household a regular income. The endlessness of the "double shift" (Durán 1986 in Torns 2006: 11) characterized by caring for her father, attending two houses, and working full-time meant that:

If someone phoned about things that were happening, debts, problems with the banks, or something else, I didn't know. I didn't see the correspondence either, because he took all the post addressed to my name when he arrived home and hid it, so I didn't know anything.

She only fully discovered the dishonesty of her husband when she took a sickness leave of absence as a consequence of cancer treatments:

One day when I felt better after the chemo I wanted to come to the AECC because here I am always busy. I had to come from the village, 50km to come and 50km to go back home. But I had a small car to go to my job. He had a bigger car too but they [Civil Guard] clamped it. They immobilized it in the main entrance of our house, So he started driving my car and he didn't want to give me my keys back so I couldn't come to see Noelia... One day I asked him for my keys because I needed to go to the AECC. I told him "give me the keys because I need them". First, he said that he wouldn't give me the keys because it

was his car, because he was the one who worked at home, therefore, he had a right over the car. Then, before he gave me the keys, he left the house and went to the car which was parked outside. I know that because I have a balcony in my bedroom and I watched him. I saw how he took a folder from under the seat and took it to the garage. After that, he gave me the keys back. At night, when I came home and I was sure he was sleeping, I told my son, remember he was only 17: “let’s go to the garage to look for something I saw this afternoon”. We went to the garage and we found the folder which contained all the post. All the summon letters addressed to my name. All of them were unopened. As of that moment I told him: “Get out this house, because if the doctors and I are fighting to cure this [cancer] so I can survive, you are destroying everything”.

Contrary to what most people think about cancer, for Amalia cancer was not as harmful and frightening as going through her destructive marriage. She clearly rationalized it by comparing her personal life to cancer itself:

Indeed, I felt quite well. Many people told me ‘but are you on holiday or on sickness leave?’ These other things I was going through were much worse than the treatments themselves. Much worse. I think I had a cancer worse than this one. It was harming me more.

Although she was on sick leave, she had to return to work in order to pay for her mortgage because her house had been repossessed by the bank. Additionally, she had to attend to many other debts accumulated by her husband. As a consequence of the financial hardships she could not finance, nor support, the education of her children as is the norm in Spain (see Reher 1997: 291), upsetting her infinitely. Her youngest son would have to leave school to help economically at home, and her youngest daughter had to drop out of university in her second year. Luckily, her oldest daughter was able to finish her degree and a PhD with the help of a grant. Remarkably, Amalia managed to sort out all of her debts and pay the mortgage with the invaluable help of her father, a cousin and her own hard work:

Well, I solved the problems as I could. My family helped me. My father helped me a lot. His support was really important. It was key to getting the divorce, facing all the expenses and debts, because I could not face everything by myself. If my father hadn't been there I don't know what would have happened. One of my cousins helped me a lot too. He was always with me, he also supported me financially. His father and my mother were siblings. Financially, my cousin was very well situated and I returned the money when I could. He is an important person because he also helped me.

However, Amalia's misfortunes did not finish despite her having suffered so many hardships. Back at her job, where she had been working for more than 10 years, she started having problems:

To my surprise, they started bullying me at work. On the basis of envy or stupid things. It was my boss. Well, the wife of my boss. She was difficult. How can I explain? At the beginning she was fine because our kids were the same age. It happened that her daughter didn't want to go to the university whereas my daughter went, and also gained a PhD. So when she asked me about my daughter and I told her, the envy started. Nobody could ask me about my daughters because, they ended up not talking to me. They started insulting her. All the time taunting me, making my life impossible. See, if my cancer was bad, if my divorce was bad, this was even worse. Much worse. Much worse. From then onwards I took sickness leave for psychological problems. My psychological health resulted in physical problems as I could not even stand still. I came to Noelia, I also went to a psychiatrist. I spent two and a half years on sickness leave because in the meanwhile I had an accident at work and the tendons of the arm where I had the surgery broke. And as you can imagine, even on sickness leave I could still hear them. They did not pay me and so on. It was awful.

To complicate things more, Amalia realized that she was unable to work in her job because her arm was irreversibly damaged by ALND and by a previous rupture of the tendons in an accident in the kitchen at her workplace:

Hospitality wasn't a good job for my arm. My job was quite hard. I had to carry lots of heavy things. I was in the kitchen. I ironed too. I used the iron a lot! And that movement was very painful.

Amalia applied for disability benefits but the application was rejected, and as a result she had to go back to her job for "six awful months. *Awful. Awful*". I asked her why the application was rejected if her disability seemed pretty obvious, at least to me. Besides, she could have official reports from Noelia and her psychiatrist to make a case.

The Breast Cancer Guide edited by the AECC (2007b: 90-98) which Noelia gave me when I asked her about what happens when women cannot go back to work, was extremely helpful to clarify my confusion, and ignorance, about benefits, sickness leave, medical examination (*tribunal médico*) and disabilities. I learned that the maximum time allowed to be on sickness leave is twelve months. If it is foreseen that the patient would need a bit more time to recover completely, she can be granted an additional six months. However, if the patient does not recover after these 18 months, her health condition must be assessed for a second time. This time, the evaluation will be carried out by a medical examination composed of various health professionals. The assessment consists of an interview followed by various medical exercises in order to determine the level of disability.

Noelia explained that there are four different kinds of permanent disability people can claim. *Partial Permanent Disability*, granted when disability or health conditions do not impede the patient from carrying out her/his habitual job. *Total Permanent Disability* is granted when disability stops people from being able to do the basic duties of their job, but does not affect their other kinds of work. With this type of disability, one can receive up to 55 per cent of the referent wage. *Absolute Permanent Disability* is when health problems completely hinder the undertaking of any kind of job or career. With this diagnosis, people are entitled to receive up to 100 per cent of the reference wage. Finally, *Major Disability* is granted when the person needs help for everyday tasks such as getting dressed, walking or eating. Although the guide describes this clearly and how people have to claim it, it does not provide information on how much money people could get so they can have an idea of their how their financial situation would be benefited, or rather, affected by disability.

At the moment of the interview 6 women, who had finished their treatments but found out they were unable to work, had applied for disability benefits. Except for Andrea and Sugar, the problem of the arm as a result of ALND was the disabling factor for four of them³⁴. The four of them described the evaluation process as “ridiculous”. I was told by Amalia and other women that it was based primarily on whether they had developed *lymphedema* as a consequence of the surgery or not. I shall remember that most of my informants had not developed the oedema pathology, or swelling in the arm, which I will explain in more detail in Chapter 6. To cap it all, women were asked to perform a series of exercises very similar to the type of movements they had to do during rehabilitation after surgery. This means that even those women who were badly affected by ALND in the context of work they had to do, were able to perform these evaluation exercises well. According to women, their ability to carry out these exercises did not accurately reflect their degree of (dis)ability to carry out their normal jobs, in everyday life.

This disagreement between women’s embodied experiences of disability and biomedical understandings of normality would be an enormous source of worry for Amalia. Social credibility posed a problem, but what posed a bigger problem was the need of an income because not being granted with the disability status, in tandem with the inability of working, would strain the financial means of Amalia - and many other women in her situation. Amalia would go on to fight in the tribunals for her health problems to be legally acknowledged by biomedicine:

It seems that all applications are rejected the first time. But I appealed. I went to a solicitor and we appealed. I already had had problems with that job. When I was on sickness leave they didn’t pay me, or they paid me when they wanted. So I became part of a Union and I went to court and all. When they rejected my application for disability I told my solicitor. He was concerned because if I left the job I would lose everything. On the top of that we didn’t have witnesses. But he suddenly said “we’ll appeal the case. Taking into account the conditions of your arm and your psychological state I think it is possible to get it”. Well,

³⁴ This number, although relatively small in my study, Noelia told me that in all the likelihood would have not been so small if my thesis had focused solely on the experiences of working breast cancer patients.

we fought for it and at the end they gave it to me. But I had to work six months there my children used to tell me ‘mum, don’t go there, it is going to kill you’.

After having a tough time in the tribunals and at her workplace, Amalia’s disability was finally recognized. Yet, in what appeared to be an ironic twist of fate, she was granted with total permanent disability. It may seem paradoxical that being granted with this disability status could worsen Amalia’s vulnerability. But as I outlined before, this scheme only covers 55 per cent of her normal wage. This situation obliged Amalia to seek another job in order to survive. However, her new “legal” status prevented her from doing the only jobs she was qualified for: catering, cleaning, and hospitality. This would pose another unexpected problem for Amalia given that her village did not offer any job opportunities at all. After much thinking she decided to move to the nearest city, Carolina. But this option would not bring her peace of mind either. Carolina was a small city which had high levels of unemployment. Hence, Amalia spent days applying for jobs.

Yeah, I am entitled to 55%, which is only 400€ a month. I can work in ‘anything’ (sarcasm), But that is the radical change of my life. First, I fought to get disability benefits because I left the job and I didn’t have any financial means. My ex didn’t pay me any pension because I was working when we got divorced, nor did he pay anything for his children. I depended on myself only. Living in the village made things even more difficult. So my idea was to get the disability benefit and then come to Carolina to find a job. It has been a big change in my life. It took me a while to decide to move to Carolina. I can’t do many jobs, I don’t only have the problem of the tendons. They removed 14 nodes, therefore, there are many things that I can’t do now. I can’t lift heavy things, I can’t do some movements when I am cleaning, There are many other things that I can do but... uff... It is complex. Because those things I can do I don’t have the qualifications for. Besides, I have the limitation of my age. It does limit me. Right now I am looking for something, but it is difficult because with the new legislation they must make permanent contracts to those who have been working there for six consecutive months. Therefore, they employ people for a month or so and after that they fire them so they don’t have to make

permanent contracts. Moreover, once you have worked there you can't work again for six months. There is not much choice here. Now I am unemployed and... I am very negative... there are some days that I accept my life, but others... Right now I have some unemployment benefits to keep me going, but I worry about what is going to happen in a few months if I don't find anything else. What will I do? I am renting a flat that I may not be able to afford by then, and I have a house in the village. But I have a house there which I can't afford with my pension. To be honest, it is true that I am negative, but the circumstances don't make things easy...

Despite the fact that she raised her siblings after her mother died, they turned away from her when her father helped her economically during her illness. Apart from her cousin, her children, her aged father, and few persons she knew from the AECC, she felt "completely lonely". With a look of sadness she told me at the end of the interview:

I believe I have a life ahead, much better than what I have had. Moreover, I think I am missing the best years of my life. Because at 56 I believe these are my best years. I am sure of it. It is when I feel more comfortable with myself. I feel like dressing up, going out, living. Living... but I can't do it because of my circumstances.

4.5. Breast Cancer and Social Inequality: Making the Links

Every single time I finished my interviews the Spanish saying "*a perro flaco todo son pulgas*" (which translates as "to a skinny dog, all are fleas" and whose English equivalent would be "It doesn't rain but it pours") used to come to my mind. Indeed, I believe the expression conveys precisely the point I am trying to make in this chapter, regarding how social difference, and hence inequality, intersects with breast cancer to make some women's experiences and situations worse and worse.

Still, the sceptic reader may wonder whether these stories are representative of something other than bad luck. After my interviews with women, my conversations with Noelia the psychologist, and my discussions with friends and colleagues working in the health sector in Spain, I can state with certainty that little about these case studies

is unusual. Perhaps, the only exceptional bits are the *floreccitas* or specific life events of each woman. These two stories, three if we take into account Andrea's experience right at the beginning of the chapter, bring to the forefront the impact of the many (invisible) social forces outlined in Chapter 2. Forces which seem to interact and build on each other to combine perversely, and violently, like a domino effect to disadvantage the already most vulnerable women. Yet, I would argue that although the intersection of these factors does produce social inequality the analysis is further complicated by the realities of women's lives.

We are now in a position to pull together some of the commonalities of the case studies. The study of how breast cancer may hamper women's ability to work in this chapter brings the issues of social and economic inequality into sharp focus. This issue problematises three assumptions mentioned earlier: The first one is that breast cancer is a disease that affects primarily young women. The second is that older women do not work. Third is that an important part of the Spanish population holds the belief that breast cancer is just a biological disease for which there are specific paths of medical treatment and therefore inequality in health does not exist thanks to the NHS. These assumptions do not match up to the facts not least because breast cancer predominantly affects older women and, because breast cancer patients (older women) *do* work within the cash labour market, but because equality in health cannot be guaranteed by the NHS and the ECSNS alone. This raises further questions about the future of survivors' quality of life and the need to match social change with reform in the current social care system to enable women to use resources obligatory for a healthy survivorship, regardless of their age, social class or geographical location. Certainly, this is imperative because there has been a growing number of women participating in the labour market in Spain since the 1980s³⁵ (Santolaria, Fernández and Daponte 2004: 25). Although more women survive breast cancer, the incidence of breast cancer rates has been on the rise for years. This means that the consequences of breast cancer will increasingly affect more and more women who are engaged in paid work.

³⁵ It was only in the mid '80s when Spanish women started entering the labour market in significant numbers. For example, in 1975 the employment rate of women was 27 per cent compared with 49,2 per cent in 2007 (Varela 2008: 223). In contrast, large numbers of British women entered the labour market a decade earlier, for instance in 1971 the employment rates were double those in Spain, at 56 per cent. In 2008, the employment rate of British women was of 70 per cent (Office for National Statistics 2009: 1). This example shows that context is a must when we attempt to compare experiences of breast cancer patients and unemployment across countries.

But perhaps even more fundamental to all of these specific problems concerning older women, employment and inequality, is an underlying but unspoken patriarchal supposition that older women do not really need to be entitled to social benefits because their husband, the breadwinner, would provide for them. Linked to this is the idea that women's wages are recreational, complementary or peripheral (Delphy 1981). This thinking, so much part of the accepted way of judging and interpreting the situation of breast cancer, helps to explain why many studies of breast cancer have for a long time focused solely on the issue of the gendered burden of care work where the woman, a patient herself, all too often has to look after her family first. This is an issue that my fieldwork also revealed as a significant factor, as we will see in Chapter 5. As a result, the importance of (un)employment in the paid labour market for many Spanish breast cancer patients has been ignored, devalued or dismissed. And as such, the experience of breast cancer patients as workers remains excluded not only from academic research but from policy circles that are ultimately responsible for implementing meaningful and effective services. An exception to this trend is the AECC. The AECC, sometimes in collaboration with ACs' Jobcentres, provides relevant information on benefits, offers workshops on confidence building, CV writing, job search support, and also provides training opportunities for returning back to work (e.g. Río et al. 2010).

It becomes extremely difficult to talk about unemployment without talking about social class, and in this thesis social class is closely tied to age and gender. Despite the importance of emphasising the experience of breast cancer as unique to women's personal trajectories, it is essential also to emphasise the impact that the social structure may have had in their individual trajectories (see Scharf 2009). Having said this in what follows I start by describing the context in which my informants live and patriarchal ideologies relevant to their socio-economic status are reviewed. This context may affect all women to some degree, but I argue that it has greater salience in the lives of older women³⁶ with breast cancer, who are now those at greatest risk of suffering from breast cancer in Spain. This allows us a greater understanding of how the context may have influenced women's gendered social class in terms of access to education or training. This may account for women's employment history, if any at all, and how it may impact on women's economic capital later in life.

³⁶ As I mentioned in Chapter 2, in this thesis an 'older' woman is defined as one over the age of 50 or who has undergone menopause.

I also need to stress here that although this context was a powerful factor in influencing older women's social class, it was not the only one. As the case studies illustrated, social class is neither a permanent nor homogeneous "state". Equally important factors such as women's marital or partnership status, family' social and economic capital, geographical location and employment trajectories and how cancer impacted in their ability to work all came into play in complex ways to counteract or reinforce some effects of socially ascribed gendered social class by building opportunities, or by limiting them. The quality of social networks was vital for this. Such realities exemplify "social class" transitions and transgressions across time, intersecting women's agency, age and access to resources.

Second, I will look at the ways in which women's age may preclude access to employment opportunities, thereby increasing their vulnerability to emotional insecurity and material deprivation. This was well illustrated by the three cases studies. In my research breast cancer patients and survivors who were older faced barriers not so frequently encountered by women who were younger. Moreover, discrimination against within employment may be exacerbated by a complex combination of causes like women's lack of qualifications and employment trajectories, disabling effects of breast cancer treatments, access to resources and geographical location. Finally, I discuss other problems with the current social care system that are important in highlighting how inequality permeates the current model.

4.5.1. Linkages between Gendered Class and Age

What is clear in the available Spanish literature is that the problems concerning women's access to the labour market in contemporary Spain and related social benefits are deeply embedded historical facts. These problems affect not just older women but women in general. However, older Spanish women are more likely to be faced with more barriers as a consequence of "cumulative" events over the life cycle. Lack of qualifications, lack of training and lack of employment experiences, compound with longer life expectancy, greater risk of widowhood and poorer health are recognised risk factors for old women's heavier risk of poverty (Ramos Toro 2006; Walker 2009), in particular because it translates in lack of resources later in life. In addition to these barriers, the disabling effects of breast cancer treatments can also add to this social and economic disadvantage.

Two delicate moments stand in the recent history of Spain: the Civil War in 1936 that lasted 3 years and the Dictatorship of Francisco Franco from 1939 to 1975. The conservative Spanish Post-War socioreligious framework is a powerful factor in explaining older women's problematic involvement with paid work and subsequent higher risk from poverty later in life, but not the only one as the case studies revealed. It has been argued that Franco's regime was a backlash for women's (and sexual minorities) rights. The regime emphasised that the woman's place was at home as a mother and wife (Platero Méndez 2009b). What is left unsaid however, it is that although the Dictatorship lasted more than 30 years, the pernicious influence of customary patriarchal ideologies about women's role in society started much earlier. Yet, as Gallego Méndez (1983) put it, these ideologies became hegemonic and successful "in indoctrinating several generations of Spanish women" (in Pérez-Sánchez 2007: 21) when Franco institutionalized them through the repressive apparatus of the state (the law, the police, the education system, the labour market) and by diffusing it through all areas of everyday life (culture) and especially through the Church (Platero Méndez 2009b, 2009b). In Chapter 6, I will analyse how this socialization may have influenced older women's relationship with their sexuality.

Although the regime relaxed somewhat towards the end of the dictatorship, these patriarchal institutionalized ideologies should be taken into account in helping to explain why few older women entered higher education (López de la Cruz 2002); why they are more likely to have more difficulties in getting access to benefits later in life including unemployment and pensions (Santolaria, Fernández and Daponte 2004; Ramos Toro 2006); and why they may face more difficulties in accessing or reintegrating themselves to the labour market. This scenario applies the current situation of many of my older informants.

As hinted at already, this social malady, which was institutionalized during the Francoist era, was not unique to women who grow up during this period. European women were afflicted too even if the malady may have affected different cohorts of women and to different degree (Cann and Dean 2009; Arber and Ginn 1991). Younger Spanish women have not fully escaped the legacy of these customary ideologies either. According to Santolaria, Fernández, and Daponte (2004: 28):

one of the biggest gender-based differences in the conditions of access and permanence in the labour market is that women are the main responsables for the housework and children's care and elderly (...) This difference reach is maximum for women aged 25-54 as women still leave the labour market in order to care for the children.

Of course, these idealized gender constructions and structural constrains clashed with the agency and realities of women's lives. Paradoxically, in spite of social norms relating to women's place in society, the widespread poverty among the population during the post war period forced many women to work out of the home at very young ages. But many women would have to leave their jobs and take care of their families once they got married because it was not socially acceptable that married women had a job (Carrasco 1992: 92). Yet some other women, even older women like Sara (61) who found an administrative position in a national company, Elisa (62) and Rosario (66) who decided to emigrate to Germany and France respectively in search of work opportunities, or Arantxa (60) who was a respected women's right activist and sexual educator, could challenge the structural forces that ascribed gender roles to them.

A part from these and many other women, the majority of Spanish older women worked as housewives after they got married. Today, however, a not inconsiderable number of these women engage in some kind of paid work, legally or illegally, mostly once children are old enough to go to the school. As the case studies illustrated, unforeseen circumstances like singlehood and migration, low income, changing family structures (e.g. divorce or widowhood), the need to support dependents (e.g. a disabled child, small children), or the need to pay national insurance to increase their pensions later on during retirement, would be some of the external forces that pushed women to enter the labour market in mid-life or even earlier.³⁷ The interweaving of individual trajectories and gendered responsibilities should be taken into account in explaining why many older breast cancer patients work nowadays in unskilled "gendered female

³⁷ Ramos Toro (2006) argues that one of the most reliable indicators for assessing the financial and health situation of older people is by looking at their marital status. First, she points out that around 60 per cent of women above 65 years do not have a right to occupational pension because they never worked *in the labour market*. Second, the fact that widowhood is an "overwhelming female condition" is significant too and adds more to the situation of vulnerability of older women. I noted in Chapter 1 that widowhood pensions are woefully insufficient for meeting someone's daily needs, at only 397.96€ a month (Navarro 2006: 97).

jobs” (Curran 1988) like in the hospitality, cleaning, and retail sectors, or in clerical positions. These jobs are characterized by being part time, temporary, precarious, low wage, and with less chance of promotion (Hidalgo Vega et al. 2007: 14; Santolaria, Fernández and Daponte 2004). I will return to some of these points later.

In addition to the linkages between class and vulnerable jobs, there is the impact of a range of events associated with the onset of breast cancer like long sickness leaves or disability. Workers in precarious jobs feared losing their work. For example, Che and Rosa Mary were threatened with the loss of customers and how this may impact on their small business. With fear of loss of customers, both women were reluctant to take days off to rest during treatments. Still there was an important difference between Rosa Mary and Che. Che was the main breadwinner and did not count with her husband’s financial (and emotional) support at all, challenging the idea that “a man automatically mitigates women’s risks of poverty” (Chant 2007:37). On the contrary, although Rosa Mary’s work was once essential to support the household when her three children were small, both her husband’s business and hers were very successful now. In that sense, Rosa Mary had more economic resources than Che who was facing imminent financial ruin.

The three case studies demonstrate the significance of the quality of social networks in constraining or enabling women going up or down the ladder of poverty. The role of social networks was especially salient when women had small children or dependents, were the breadwinners of the household, or faced financial hardships. I will illustrate this point in the next chapter too.

From the narratives we could sense that the corrosive effect of worrying for money and unemployment can have a deep impact on women’s well-being. I observed that the employment fortunes and fates of unskilled breast cancer patients differed in important ways from those who were semi-skilled or worked in managerial or technical professions. In general, women who worked in managerial or technical professions like Cayetana who was a doctor and a lecturer, Inma who was a teacher, Barbara who was a civil servant in a day nursery or Carlota and Mari Mar who worked as auxiliary nurses in public hospitals, were not as worried with job loss. This is not to say, however, that women were not concerned about the impact of treatments on their job performance.

4.5.2. Age Discrimination

Breast cancer patients and survivors faced other burdens when they sought a job. When older breast cancer patients like Amalia, Andrea, Eva or Julia wanted to work during their illness or after recovery, finding a job proved to be very difficult because they were regarded as undesirable by an ageist labour market.³⁸ For these women who were in their mid forties and fifties, the situation was even more complicated if they lacked “occupational” skills. It was felt that that combination of their age with lack of education and professional skills blocked any attempt at re-entering the labor market. Ironically, the few jobs available for older, ‘unskilled’ women to apply for often required a significant amount of physical activity. These were precisely the jobs women could not do a consequence because ALND had seriously compromised their arm mobility and strength or caused immense pain (see AECC 2007b: 98; Ríó et al. 2010: 144).

For example, in a very similar story to Amalia’s, Eva who had worked for more than 30 years in the car industry had to leave her work because she “was not physically the same after finishing treatments”. Given that she was granted with total permanent disability following a hard battle in the Tribunals, she only earned “300€ per month after 30 years paying taxes!” Total permanent disability meant that she could no longer do the only job she knew and loved and now she faced job discrimination. Eva’s experience speaks for Amalia and many other women in a similar situation (Walker 2009: 148). She perceived that she did not find a job because of her age, her disability and her lack of qualifications. To complicate the situation more, Carolina was a city that did not provide a vibrant job market either. Eva said:

I want to work but I don’t find anything here. I have problems in the labour market because I’m 50 and I am not qualified (*no estoy preparada*). I mean I am qualified for what I have done all my life. I’m very good at that. I don’t understand about other jobs. However, I think I can learn but there is not any

³⁸ Laczko and Phillipson (1990: 87-88) note that the widespread belief that old people are handicapped in terms of work simply by virtue of their age which, supposedly, makes them less dynamic, less flexible and able to adapt to new situations, still rings true when it comes to employment practices. For extended analysis on the discriminatory ageist practices of the labour market see also Hult and Edlund (2008); Greengross (1990); and Castaño and Martínez-Benlloch (1990).

chance from the very moment I disclose my age. I don't feel I can start studying now.

Unlike, Amalia or Che, Eva had a loving husband who worked in a good job. This meant that she did not have the additional stress of lacking enough money to live. Nevertheless she perceived that her situation was unfair given the additional stress of suffering from cancer and losing her job. With a mix of anger and sadness she told me:

I have been six years without working (on a permanent basis) and I feel super empty... I feel I worth nothing, I feel bad. I have a big sense of emptiness because of this. When I talk about this I am told: "but your husband works", ok, but my husband is my husband I am I. Many women of my age have a different approach to life (sigh). Of course things are working at home but I need to work, I need to have my job.

The impact of breast cancer in women's employability resonated throughout many interviews with women and conversations with Noelia. My research shows that older women who underwent ALND, did not have qualifications and lived in geographical areas characterized by high level of unemployment like Carolina, were more likely to become unemployed than women who were more qualified, younger, or that lived in an environment that provided more resources. As the three case studies showed, the situation of unemployment and the financial impact of breast cancer is likely to further exacerbate women's suffering in a number of ways, including poverty, material deprivation, social exclusion and mental health problems like depression, anxiety, feelings of powerlessness, insecurity or low self-esteem. This situation has a clear potential to disrupt family functioning and burn out social networks increasing significantly women's mental health problems.

4.5.3. The Social Care System

Other problems with the current social care system would include unequal access to financial resources. The case studies showed how women were discriminated against when they tried to get disability benefits for the side effects of ANLD. This was an area of concern for Noelia too who saw how the suffering of many women multiplied with

the dramatic accumulation of stress due to living with breast cancer, coming to terms with a disability and the prospect of losing their jobs. For example, the harrowing side-effects of breast cancer treatments would leave such a mark on the bodies of Andrea, EllaSerYo and Sugar that they would be unable to return to any kind of work. Hence they would be granted with absolute permanent disability that made possible to earn 100% of their previous wage. However, other women like Blanca, Eva, Amalia or Julia would have to “*pelear mucho*” (fight a lot) in the tribunals to get their disability recognized. They complained bitterly about the role of health professionals and other social institutions in deepening the injustice since the biomedical gaze failed to recognise, and legitimise their disability or pain. I will explore in more detail the discrepancies between biomedical knowledge and women’s embodied experiences in Chapter 6.

Moreover, the social care system failed to provide alternatives a healthy survivorship. Noelia would tell me that it seems to be a growing recognition, minimal but recognition nonetheless, among some health professionals that ALND might impact negatively on women’s ability to work. Lots of bureaucracy, knowledge and determination made it possible, sometimes and for some women, to be granted with total permanent disability. But far from helpful, as the case of Amalia illustrated, this may result in two interlinked problems. I explained earlier that total permanent disability does not pay the full wage affecting seriously women’s income. Therefore, women need to carry on working but have little options because they cannot continue to work in the same job that when they became disabled, which are precisely the only jobs they were qualified for.

This brings to the fore another problem. All the women I spoke about this issue were members of the AECC. In this context, the AECC was key to help women navigate the complexities of the system. It provided information and advice on how to claim their legal rights. If needed, it also provided psychological reports. More research would be needed to analyse how women who are not members of the AECC fail to claim or obtain their legal entitlements, because they do not know their rights and the rules.

One further paradox of the shortcomings of social care is that it should benefit all breast cancer patients, especially those who are more vulnerable, but it seemed to conspire against them. We saw how the social care system penalises in other ways those

who did not conform to the dominant gendered constructions of the ‘normal’ worker, which also affects breast cancer patients. For instance, when Che’s husband was fired for taking paternity leave. This also affected her experience of breast cancer, although indirectly. Another example is that of the gender inequality in entitlement to pensions. In many situations, even where women had been working all her life caring for their households, they were not entitled to occupational pensions. But even when women did engage in paid work at some point of their lives, it was very rare for them to enjoy the full range of social protection of full time permanent jobs like pensions, promotion or training that could benefit women not only on economic terms, but by improving their chances to find employment for the unforeseeable future. Unexpected circumstances that affect women’s finances like widowhood, divorce or illness of the spouse to name but a few, can force women to engage in paid work in an attempt to regain control over their lives. Ironically, disability caused by cancer will hit them especially hard by blocking their employment aspirations and needs. Those who owned small business were also discriminated against. While the threat of losing their job was expressed by all self-employed women, those who did not have additional resources to keep the business afloat or to make ends meet were more affected.

Although paid work may not be always a choice, women talked of the different ways in which they enjoyed their jobs. Sometimes paid work provided financial independence, sometimes it was described as a break from their mothering and housewife roles, and sometimes women simply and plainly loved it. Enjoyment, often complicated by economic difficulties, personal circumstances and ageist attitudes, enhanced women’s feelings of uselessness and hopelessness when they were unable to return to the labour market or access full benefits. Evidence also shows that people are better off in work in terms of their health and well-being, their self-esteem and the future prospects for themselves and their family (Siegrist 2009).

4.6. Conclusion

Sered and Fernandopulle (2005: 18) argue that “illness disrupts household income and interferes with rent or mortgage payments, it also can lead to bankruptcy”. This is exacerbated by the length of treatments, the impact of disability, or unemployment. Therefore being in a position of social inequality means that having breast cancer is

more likely to make your position worse, and start a downward spiral of poverty. In this chapter we have seen that breast cancer is inequality embodied and materialized. I hope I have shown how the real pathogens in this fight are not only cancer cells but also sexism, ageism, classism, emotional minimalism and the antihumanitarianism of biomedicine (Spence 1988; Sered and Tabory 1999; Good 1994) and, why not, maybe lack of empathy from society. It is my informants' "aspiration" (Appadurai 2004) that we take the oppression of these violences seriously. First, there is a need to keep a record, describe and make visible the direct relationship between social inequality and breast cancer experience. This chapter is particularly useful for providing a new framework for understanding the layers and layers beneath social inequality. It illuminates how social inequality is both embodied and materialized in the experience of breast cancer, and how it discriminates more against the most vulnerable women.

Second, this chapter voices women's demand for a coordinated collaboration between policy makers, health professionals, charities, the family, social networks and the social care system. If something needs to be highlighted here, although it needs further research, is that it seems the AECC is the only pathway available for women to get comprehensible information about how and where to claim benefits for their disability. It would be interesting to know how those women who are not familiar with the AECC deal with their disabilities, whether their information needs are satisfied, how and by whom.

Third, organizations, professionals and policy makers working with breast cancer should take into account how issues of gender, women's social class, age, arise, operate and intersect with each other and women's personal biographies to impact all dimensions of breast cancer experience, whether on physical health, employment, applying for benefits, accessing resources, or socializing.

Ultimately, however, there needs to be a fundamental rethinking of the social institutions in Spain such as the social care system, including the labour market and the welfare state. Until the harmful unequal gender ideologies underpinning these structures are addressed, these systems will never be able to ensure an equitable distribution of resources and opportunities, nor, therefore, guarantee women's full participation in society.

By unravelling how social forces linked to patriarchal ideologies, intersect with social structures, the effects of treatments and women's unique lives, this chapter clearly

shows how breast cancer experiences and the inverse care law are clear. Thus, inequality in breast cancer definitely exists. According to my informants, if these linkages remain invisible, the repercussions of breast cancer will remain, and will violently reproduce an endless vicious cycle of suffering, which unfortunately affects those women worse who are more vulnerable and need help more.

Chapter 5

Social Networks and Women's Health

5.1. Introduction

In the last chapter we learned how and why older women and women from lower social classes were more likely to be victims of structural violence, a violence which has its roots on the inequalities of society, and which seems to reproduce itself in the form, of ageism, and sexism, in tandem with the reductionist, materialist and antihumanitarian biases in biomedicine. This way of looking at inequality defies research and practice based on assumptions which reduce the relation between breast cancer and social inequality to simply economic terms. Hence, the example of (un)employment was particularly useful for identifying how structural forces, whether from state and non state authorities, affect, shape and conspire to create inequality.

In this chapter I move to explore how inequalities of the social structure are recreated through the practices and attitudes of women, their families, their friends and other social networks. The question I seek to examine is whether social networks may reveal a generalizable cosmology, and if so what that reveals about the societal beliefs of contemporary Spain. Yet, I am aware that this view is partial as unfortunately the experiences of many women are not included in the analysis.

This chapter postulates that even in the most “harmless” of personal relationships, for example that of wife and husband, which, although it is constructed in the name of altruism, love, and friendship, satisfies societal norms and values on gender, social class and age. As such, these constructions have a tremendous impact on women's experiences of breast cancer, but also on their husbands or male relatives. Important for this thesis is that the same cosmological visions which rule social relationships allow us to uncover positive values and spaces for women's agency that are precisely harboured within those constraining ideologies.

5.2. Defining Social Networks

The battle against illness is so hard that not only the ill person fights. Family and friends also fight against it by passing their strength and resources to the patient. The healing nature of these social networks, which support the diminished resources of the patient regardless of their class position, should never be underestimated. However, not everybody transmits a positive flow of energy, there are some persons who add unnecessary drama to the situation (Durán 2003: 45)

Popular notions about social networks that are prevalent today are largely infused with the romantic idea that they constitute a largely harmonious unit which provides support and empowerment. Indeed, social networks have been defined as “the channels through which pragmatic help as well as emotional and psychological support can be exchanged between individuals” (Achat et al. 1998: 735). These beliefs are in accordance with most of the literature on breast cancer and social networks, as well as with my informants’ experiences. Indeed, these women would agree that social networks contribute to their social, emotional, physical, spiritual and mental health (Eguino Villegas et al. 2007; Bloom and Kessler 1994). Most would also agree that lack of social networks such as nuclear family, relatives, friends, neighbours, or group membership would cause them great suffering.

From the beginning of my research, however, women’s accounts strongly resonated with María Ángeles Durán’s (2003) words about the complex, and sometimes contradictory, nature of social relationships. This prompted a number of questions. Given that each breast cancer patient is an individual³⁹ and that her relationship with her social networks may not be *solely* harmonious, are widespread beliefs about the positive role of the social networks actually empirically justified? Or, is it possible that social networks are a source which causes more distress than healing to breast cancer patients? Moreover, can loving and caring social networks cause suffering? On the other hand, can the same loving relationships which cause distress also create an enabling environment for women’s recovery? That is to say, a source which provides relief,

³⁹ According to Pool and Geissler (2006: 119) ‘individual’ implies a “sense of a specific construct of the person that stresses autonomy, separateness, independence”.

information, support or even healing to women? How is this contradiction possible? Considering that cancer is a stressful condition which can impinge on all dimensions of women's lives, from health to employment, housing or social participation, I wondered whether women's social networks would be affected, and whether structural forces would play a role in this.

Traditionally, the role of the family and social networks in illness has been studied, and described, as a source of unified interests and altruism (see Rico 1996; Pearlin and Aneshensel 1996). For example, media, political and religious discourses portray the Spanish model of the family as a site which provides "the most important source for affection and care for the ill" (Eguino Villegas et al. 2007: 77; see Reher 1997; Valera 2002). More recently, however, feminist scholarship has pointed out that social networks, especially the family, are also a complex site for conflicting values and tensions (Pichardo Galán 2009; Hartmann 1987; Jackson 1997; Jamieson 2003; Kynaston 1996; Leonard 2001). In practice, at least when it came to my informants' experiences, these differences were not that clear-cut. In women's experiences, social networks embodied all at once both these contradictory views about social networks.

Social networks mean different things at different places to different people. For some, they mean the nuclear family, relatives and friends. To others, it includes support groups and neighbours. Anthropologist David Jacobson (1987) argues that defining social networks may be problematic for two main reasons. First, because there is a widespread assumption that receivers and givers of support interpret help in the same way, which may not actually be the case. For instance, whereas some husbands of breast cancer patients saw themselves as being very supportive because they helped with the domestic chores or accompanied women to their medical appointments, some women may not see this help as sufficient or satisfactory. Indeed, for some women what was needed most (at some points) was emotional support from their partners. The second problem lies in cultural definitions of what counts as support and what does not. That is to say, classifications may clash or, on the contrary, fall short of specific cultural beliefs and practices about social support.

To illuminate these discrepancies in the definitions of social networks, I adopt David Jacobson's (1987) concept of the "cultural context of social network". According to Jacobson what is more important when naming and framing social networks is not so much "the attributes of an incident or an interaction", but how women "evaluate or

interpretate” whether a behaviour is supportive or not. And this exercise requires an examination of the socio-cultural context. In other words, it requires an examination of women’s beliefs, values and norms about social support (Jacobson 1987: 43). As we will see in this chapter, to many of my informants the definition of social network also included the AECC and *la calle* (the street). Understanding women’s definitions of social networks is the first step to bridge the gap between experts’ knowledge and women’s needs.

In this chapter I attempt to examine the role of social networks in women’s health as defined by women themselves. The aim is to explore women’s social networks as enabling women’s well-being but also as a source of tremendous distress. First, I will begin by exploring how the family and other social networks such as the AECC and *la calle* may become a safe place for women to talk about their emotions, regain strength, find information about their illness, as well as economic and emotional support. In the second part, I will explore how unconsciously assimilated gendered roles manifest in social networks to trap women and their families in conflicting values and tensions. For example, for many women the role of mothers and wives conflicts with the role of patient, affecting their well-being and compliance with treatments. The gendered *marido mudo* (mute husband) who does not express his feelings and opinions was also seen by women as a source of affliction and distress which could lead to conflict.

5.3. Exploring Positive Roles of the Family and Social Networks

In general, *la familia* proved to be a protective site where women could find security, reassurance and support. In my study, unless the woman was divorced and single, the definition of *la familia* always included the partner, children, siblings and parents. In the majority of cases it also included *some* cousins and relatives, not so much based on a hierarchy of blood but on the nature of the relationship (*el trato*). The protective nature of the family was essentially connected to images of home (*casa*). Home is described by Manuel Delgado Ruíz (2005: 55) as an intimate space characterized by “certainty and trust where one expects to experience affection and the opportunity to be the imagined self”. One woman, Melissa, a breast cancer survivor, felt so strongly about this that she told me:

Where I found myself marvellously was at home. My house was like a wall, a protection (Melissa).

However, this very certainty is dependent on the extent to which gender roles, and of which kind, are routinely performed within the home. It also depends on the relations within the household as the case of Amalia illustrated in the last chapter. In other words, at the same time as the family-home entity may be supportive, its normative nature could also oppress women. In these occasions it is where the “indetermination” (Delgado Ruíz 2005:58) of the street or the empathetic understanding of the AECC became liberatory and therapeutic. I will return to these points later in this chapter.

Noelia’s extensive experience with cancer patients had shown her that support from the family can exert a powerful influence on improving women’s quality of life. She explained that the family is crucial in alleviating women’s feelings of anxiety, loneliness or alienation. It enables women to accept and come to terms with their illness. This, in turn, facilitates illness management in terms of care continuity, compliance with treatments and decision making (see Collie and Long 2005: 846).

Before going further, it is important to clarify that, as a matter of fact, support during the therapeutic process was not always received from *all* members of the family. Whereas some women received most of the help from their husbands, others received help from their sisters, siblings, parents or even cousins. The older women in my research, for example, usually received help from their daughters. Yet, it was all defined as “help from the family”. I also want to emphasize that some members could be supportive in certain instances but at other times not be helpful at all, or even became a nuisance, as I will explore in the second part of this chapter.

There were four main types of family behaviour which women defined as supportive and enabling: help with the domestic chores, emotional support, support to navigate the world of biomedicine, and economic support. I will explore these understandings of support in what follows.

As we saw in Chapter 2, when we discussed the gendered dimensions of breast cancer experience, the difficulties with housework and the lack of help at home were cited by women as important factors affecting their mental and physical health. In spite of this, when directly asked about who helped them at home after receiving treatments, women’s more common responses were “family first” (Jacobson 1987: 50). That is to

say, the help received primarily came from husbands or partners, children, parents and siblings. More specifically, following what Jacobson defines as the “gender rule”, after husbands, if not concurrently, the support came from daughters, mothers and sisters.

If we give a closer reading to narratives, help was received mostly during extreme bouts of weaknesses, or when the effects of treatments were clearly visible (e.g. vomiting). The temporary nature of this help would upset women and would be experienced as source of tension at home. However, contradictory it may seem, it is poignant that *any* help with the domestic chores was experienced by many women, especially older ones, as a “blessing” which ameliorated women’s stress. Let me try to untangle this contradiction.

Gendered thinking among women emerged through their use of the words “blessing”, “support” or “*amor*” (love). These words imply the cultural idea that housework is a woman’s responsibility. Hence any kind of “help” with domestic chores was not understood in terms of obligation or distributive justice in sharing household burdens equally, but more like a beneficent act. Elisa, who was in her sixties, illustrates this well:

Si, si, si, si. Support... I mean that for example he [her husband] doesn’t like to do any housework and I saw that he did. He did something. For example when we came from chemo he used to say: ‘eat something and I will tidy it. I’ll do the washing up so you can rest’. Si, Si, si. He supported me.

Not always was this was the case though. Eva, for example, was very assertive about who undertook housework responsibilities. At home, she told me, “it’s imperative that everybody (her husband, son and herself) do their share equally”. Indeed, according to this idea of equality, Eva’s husband did contribute extra to the household chores when she was particularly weak as a consequence of treatments.

Similarly in the way women tended to praise their families when they did help with the housework, at some point or another during the interviews, the majority of women also expressed that they felt that their family was patient (*paciente*) with them. Like a blessing, patience (*paciencia*) did not simply relate to the lack of complaints about women’s mood swings and “gloom”. It could relate to women’s attempts to praise their family’s lack of complaints about the transgression of gender-specific rules such as

asking for help, “neglecting” the management of the house, or even abstaining from sexual relations (Sulik 2007 in Chapter 2). For example, Poliana, who was 59, insisted on “the humanness” of her husband in all aspects of their relationships. But she justifies her husband’s “infinite” patience because he did not put pressure on her to resume sex even well a year after treatments finished:

Ana: And who helped you when you were weak?

Poliana: No, no. Because my husband is a very tender and delicate person. He had a lot of *patience* and care. Because I didn’t know when the right time was to resume our relations. Therefore he had an infinite patience. When we considered we could have [sexual] relations... because we were no longer afraid of harming me, we did it. I tell you, my husband is a great person.

A different theoretical position about the relationship of women and their compliance with gender roles has been put forward by Unnithan and Srivastava (1997). Applying their model, one could analyse women’s praise not merely as a response to a romantic vision of an ideal of manhood, nor as an act of gratefulness, but as a strategy. Within this idea of praise, support is not presented as natural in a democratic household, but is recognised as an exceptional consideration. This strategy is effective because the family is made to feel proud of its role of “benefactor” so it keeps providing support.

Gendered or not, liberating or not, there is no doubt that women were appreciative for *any* support received at home in the form of cooking, doing groceries, washing the clothes, cleaning, ironing, or the like, this was especially true when women were undergoing treatments.

As we saw in Chapter 4, economic support offered by social networks should not be underestimated either when trying to understand the impact of cancer on women’s lives. Even though all Spaniards are entitled to free NHS treatment, it should be clear by now that breast cancer impacts on women’s economic status by affecting their earning capacity. In her autobiographical writing on the experience of having breast cancer, sociologist María Ángeles Durán notes:

The worst thing about the illness is that normal circumstances disappear immediately, not only the spending increases but the earning decreases together with those invisible resources associated with employment (Durán 2003: 51).

Reduction in working hours, sickness leave, partners' time off work to accompany women to medical appointments or care for them, hiring domestic help, seeking CAM, buying wigs or mastectomy bras (which according to my informants "are outrageously expensive") add to the financial constraints triggered by cancer.

Although a very extreme case, Sugar explained how her family's financial support played a major role in her survival. She recalled with resentment how seven years ago she was literally given a death sentence (*desahuciada*) by the NHS. She and her family refused to give up hope and sought treatment in the private sector which cost her family a fortune in terms of money, properties and access to leisure.

We sold a flat I had in order to receive treatment. But given that I didn't have insurance I had to pay in cash. That it is the reason I know how much the *Excertin* (a drug) costs, because I had to pay for it. That time, in my first treatment, I spent twelve million of Pesetas (£72,000) in just six-eight months but nobody knows how much this illness costs in terms of money.

Although Sugar had had several recurrences and liver and lung micro-metastasis, she told me that for her family money was no object if they were to pay for the latest treatments available. In addition to conventional cancer treatments, Sugar used CAM regularly. Among some of the CAM therapies she had tried were *biofeedback* and *naturotherapy*. The appointment for a doctor who supervised an *orto molecular diet* "cost €150, and prescribed drugs cost more than €400". Sugar had also travelled with her daughters and husband to Japan in order to meet a healer by recommendation of a friend. When I met her she was taking 8grams of *curcumin* daily. I asked her what curcumin was. She explained that one day she was surfing on the Internet to find out about the latest treatments available and clinical trials, and she learnt that research with curcumin was being done pretty successfully in the MD Anderson Cancer Centre in Houston (the same private hospital that treated her in Spain after the NHS had declared her to be terminally ill). She sent an email to the principal researcher asking for

information. She was told that although there was no conclusive data of its efficacy, she could try taking doses of 8 grams orally on a daily basis. Even if it did not work with cancer, curcumin had other beneficial effects on health⁴⁰.

Although curcumin was very expensive at the chemist, Sugar could afford it because one of her daughters worked as an airhostess. For example, curcumin was much cheaper in the USA where “\$15 of curcumin would cost \$60 in Spain”, so whenever her daughter flew to the USA she bought it for her.

Sugar was very conscious that these treatments were unaffordable for many women in her situation because these therapies were not covered by the NHS. Besides, CAM tends to be very costly. She knew she was fortunate because her family was very supportive not only psychologically but also financially. Moreover, they had the means and financial resources to help her.

Everything is about money. Everything is translated into money. I know this now. But I don't mind. It's what I want to do. It's my life. These have been seven years that I gave to myself. For me, they are worth all the money spent. Well, this is thanks to my family which has been supporting me all the time. However, I never go to the hairdresser nor to the cinema but we don't mind spending money on the latest nutritional treatments or things like this! (laughs).

The case of Sugar illustrates how the financial support of the family solves a host of problems for women, ranging from providing “luxury” CAM to the more hidden strains of “making ends meet” as we saw in the case of Amalia.

However, although I do not have enough the data on this, I believe the willingness of many families to financially support their loved ones may be hindered by the reality of their economic circumstances. Indeed, unfortunately, evidence suggests that the benefits of healthy living, leisure, and CAM treatments are out of reach for many (breast) cancer patients who cannot afford them (Boon et al. 1999).

The role of the family was also crucial in helping women navigate the world of biomedicine. Most of my informants were accompanied to medical appointments and

⁴⁰ Aggarwa, Kumar and Bharti (2003: 363) in reviewing research done on the impact of curcumin on health concluded: “In several systems, curcumin has been described as a potent antioxidant and anti-inflammatory agent. Evidence has also been presented to suggest that curcumin can suppress tumour initiation, promotion and metastasis. Pharmacologically, curcumin has been found to be safe.”

rounds of treatment by their husbands or partners. When this was impossible because of the demands of husbands' work, women were accompanied by grown-up children, usually daughters, mothers or sisters. Research has shown that in such stressful situations women are usually very anxious, and it is very unlikely that they are able to ask "proper" questions about the disease, different treatments available, importance of procedures, side effects or types of care needed (see Chapter 1). The Department of Health (2000: 64) notes that "patients remember one tenth of what they were told during a consultation". In other words, women are not able to assimilate and understand information that they would understand if free of stress or in normal circumstances.

In this sense, the family proved to be practical for various reasons. First, like home, it provided a sense of physical security. Familiar company was felt as comforting in an unfamiliar setting. Second, it functioned as an "external hard disk" which backed up all the information received during the appointment. This way women could double-check that they understood the information correctly: their diagnosis, cancer stage, options available, and what had to be done next. Finally, the family helped to translate "medical jargon" into ordinary language (see Pitts 2004). For instance, Maribel explained how her husband had the idea of recording the first appointment with the oncologist in order to facilitate their understanding of her medical diagnosis:

We took an mp3 with us to record the conversation because it was the first time we spoke with the oncologist and we were a bit... we thought we wouldn't understand the conversation very well and we wanted to reflect upon it afterwards.

I described in Chapter 2 that patients who enter the world of medicine find that they are faced with the unintelligibility of the "loquacious medical gaze" (Foucault 1975: xi). In this highly specialised world, even the most educated women were confronted with alien medical language, the hierarchies of medicine, gender and age. From women's experiences the support of the family, and other social networks, was essential in empowering them by facilitating the process of "learning the medical language" (Good and DelVecchio-Good 1993) together, particularly pre-treatments: from understanding the illness to knowing the best treatments available, where they had to go or reclaiming from doctors their right to make decisions.

As we have seen, by helping with the domestic chores, by helping to navigate the world of biomedicine, and by providing economic support, the family does not only provide a sense of psychological and physical security but also emotional support.

5.3.1. *La Asociación*

Nearly all my interviews took place at the headquarters of the AECC and therefore this section reflects only beliefs and ideas of those women who are familiar with *la Asociación*. Women were either members of the AECC, volunteers or clients undergoing psychological treatment. I was told that, in general, women came to the AECC seeking psychological treatment at the beginning of the therapeutic process, and ended up registering as members. Some of them decided to volunteer by organizing many of the social activities carried out by the AECC. Others preferred not to volunteer, but still wanted to be part of the activities and festivities. These high levels of women's involvement in one way or another, evidence how the AECC was considerably successful in meeting women's needs regardless of their stage during the therapeutic process and well after treatments had finished.

As was outlined in Chapter 1, the AECC provided a wide range of social services and therapeutic options free of cost. Given that the AECC was well known in the country, the majority of women who sought psychological treatment were referred by their doctors, nurses or by recommendation of friends, family or acquaintances who knew of someone who had received treatment there.

That the services by the AECC were beneficial and empowering was an oft-repeated theme in women's narratives. *La Asociación* was presented as a liberating site for several interrelated reasons already sketched out in Chapter 1 but which I will develop further in what follows. First, *la Asociación* played a significant role in women's socialization. Second, it provided therapeutic healing. Third, it provided the opportunity to learn first hand about the illness (e.g. medical jargon, symptoms, stages, treatments, facts). Fourth, it provided its members a sense of community and political unity.

Services provided by Noelia were the most used and praised by women. She provided practical information on finding resources such as where to find affordable wigs or breast prostheses. She also offered information on health-related problems such as prevention and rehabilitation of lymphedema, which was often overlooked, as we

will see in Chapter 6. Noelia suggested tips on nutrition and body care (e.g. how to care for burnt skin during and after radiotherapy). Frequently, women learned this information during the first appointment for individual psychological therapy. On top of these “practicalities” women learned coping strategies to manage fear of cancer or treatments, alleviate emotional distress, or facilitate communication between family members. Noelia’s main objective was to “improve women’s quality of life” whatever the stage of the therapeutic process. The following quotations illustrate how psychological therapy improved women’s well being:

I was seized by panic. I couldn’t fight against it so I called Noelia. She gave me an appointment and I’ve been coming for three years now. Noelia helped me a lot to understand many things, to understand the disease (Francisca, 41 years old, she was 37 when she was diagnosed with breast cancer).

Thanks to Noelia because I was... Goodness! I was very depressed! (Daniela, 80 years old had cancer 11 years ago).

Chemo was getting worse and worse. To the extent that I decided to come to see Noelia. She gave me some tips to relax before the cycles. Because I was unable to relax, I started throwing up before treatment, from the very moment I sat in the chair. More and more throwing up. It was bad, bad, bad (Sara, 61 years old she was diagnosed 6 years ago).

She showed me how to do relaxation exercises for when I was anxious. She gave me tips about healthy eating. Because when we’re with having chemo we don’t eat, we don’t have any appetite, we’re not hungry. We’re just sick. She told me about eating five meals a day, fruit, vegetables... She taught me how to do a healthy and compulsory timetable (Mari Mar, 40 years old, she was diagnosed 18 months ago).

Other therapeutic options available at the AECC very much appreciated by women were: psychological group therapy, volunteer testimonials, and various social activities like outings, fundraising days, handcraft workshops, seminars and the like. Therapeutic

is the best adjective I can find to describe these services as they were successful in “ameliorate a sense of loneliness and normalize a process that had felt alienating and isolating” (Pitts 2004: 46). In the AECC both cancer patients and survivors found a space to freely express their unspeakable feelings and to be understood. Feelings of grief, anger, loneliness or fear that sometimes had to be repressed at home to minimize the anxiety of family, friends, colleagues and others. Here is the example of Francisca. She felt so strongly about the need to protect her daughter and husband from her own thoughts that she suffered in silence. One day, after she had had her surgery, she saw an ad of the AECC when she was watching TV. Straight away she phoned to *la Asociación* and asked for an appointment with Noelia.

I’m speaking my mind. I told her [Noelia] many times that thanks to her and my husband I am here now, otherwise... At the beginning I wanted to die. I was terrified of dying, of suffering and everything else that was coming. As a result I was unable to reason. I thought it was easier to die. I used to say: ‘what about if I jump out the window?’ But then I thought of my husband and my daughter: ‘If I die, if I disappear, they will suffer’. That was what made me fight. Yes, I had that kind of thoughts. But I was a coward, or perhaps I was very brave to go on...

Lowering her voice to a whisper, Francisca told me that she had never ever discussed the issue of suicide with anyone else apart from Noelia. When Francisca was talking I could make out a trace of shame and guilt in her face. I reassured her by telling her that those kind of thoughts were more normal than what many women would acknowledge in public, or even in a safe space like *la Asociación*. Fortunately, many breast cancer patients did not need psychological care post treatments, but others like Francisca continue to need occasional therapy sessions despite she was diagnosed three years ago.

Apart from very specific issues, like for example suicide which is still a difficult topic to speak about in public, in general women liked to talk with each other about their experiences. In *la Asociación* they could freely perform their sick role and leave behind the “cheerful mask”. They felt that they could ask and talk endlessly about their experiences, symptoms, and choices without worrying about the feelings of the listener (a non-cancer patient). As they explained to me they “can talk and talk without

worrying, upsetting or boring the others because we women here understand each other”.

In line with previous research on breast cancer and support groups (e.g. Pitts 2004), exchanging experiences with other women was a way of corroborating that the symptoms that they were experiencing were normal and were not in their heads. This exchange of information helped dispel doubts or fears of abnormality or recurrence. For example, Carmina who was diagnosed a year ago liked to chat about her illness with other breast cancer patients and survivors. At the moment of the interview she had finished chemotherapy and radiotherapy treatments and was waiting for her forthcoming breast reconstruction surgery. She expressed her fears of the surgery. She felt that she had a lot of biomedical information on the procedure but she did not know anyone who had undergone the same sort of surgery with whom to check the “pros and cons”. All her friends and acquaintances had undergone reconstruction with *expander implants* but doctors had recommended her *TRAM (pedicled transverse rectus abdominus myocutaneous) flap* as her best option.

The common view was that TRAM flap was much more complicated than reconstruction with the expander. Certainly the latter is a far more complex procedure because the muscle from the abdomen is “used to carry the lower abdominal skin and fat up to the chest wall” (BreastReconstruction.org 2010), whereas the reconstruction with expanders :

allowed the implant to be placed beneath the residual skin and muscle [of the mastectomized breast] while uninflated. Once the skin and muscle flaps recovered from the trauma of surgery and could tolerate the stress, the implants were inflated (de la Torre Vasconez 2009).

The implication of this is that TRAM flap surgery takes much longer to be performed, so does the recovery, and has more possible subsequent complications that major surgery entails. Carmina was uncertain about the need for that surgery because the disadvantages (at the very least a long and painful recovery) outweighed by far the advantages (more natural touch and look, but not feeling). She told me that the terror of the surgery was distressing her sleep by night and her functioning by day. As she was very upset I felt the obligation to share humble information with her. Suddenly I heard

myself saying: “I don’t know if this is of any help to you, but I know some women who underwent a similar surgery and are doing fine”, to which she replied:

Yes, I do find consolation in your words. Indeed, I am looking for women to talk to, women who underwent the same surgery, or surgery on their back⁴¹ because it’s very similar to mine. I’d like to talk about it. I only know one woman, all the others had surgery with the expander. Will I make a mistake?

I thought aloud whether it would be a good idea to ask some of my informants who underwent *LD Flap* (*Latissimus Dorsi Flap*) surgery for permission to give their contact details to Carmine. This way she would be able to ask them all the questions she needed to lessen her dread. As Carmina was telling me, “who would be better placed to advise me, or provide information about it, than someone who has experienced the surgery?” I asked her what she thought about my idea. With a smile and an expression of enthusiasm in her eyes she said “that would be awesome!”

However, the AECC was not a naturally empowering site for all members though. Indeed, some women were not fond of joining therapies or social activities. In the case of Blanca, who was diagnosed four years ago, coming to the AECC was a reminder of her vulnerability. The awareness that she was struggling with the painful and disabling effects of lymphedema and that she could not work nor obtain disability benefits were as bad as the whole trauma of being diagnosed with breast cancer. Thus, any potential benefits of socializing in the AECC were outweighed by unwanted reminders of the precariousness of her current situation.

For two very different reasons, Cayetana and Gema did not enjoy being part of the active life of the AECC either. Both of them made clear that they did not have any problems about talking about breast cancer. For example Cayetana had a close bond with the AECC by virtue of the psychological support she received but she did not identify herself with the other women. Besides, she told that she had always been very reserved about her personal life and cancer was not an exception. She hardly liked to

⁴¹ *Latissimus Dorsi Flap* is pretty similar to TRAM. Basically the surgery is done with muscles from the back and not with the muscles from the abdomen. BreastReconstruction.org (2010) defines LD Flap like this: “at the time of breast reconstruction, the muscle flap, with or without attached skin, is elevated off of the back and brought around to the front of the chest wall. The main vessels remain attached to the body to ensure proper blood supply to the flap. The LD flap provides soft tissue to allow complete coverage of an underlying implant”.

talk about her private issues with anyone, not even with many of her friends or relatives to whom she did not disclosed she had suffered from cancer.

Gema's reasons were of a different nature. Although *la Asociación* was in general a safe space for women, I do not wish to deny that it surely was not free from occasional tensions and conflicts between its members. Of course this problem is not limited to the AECC Carolina and it is the rule in any organization. However, the only conversations or special references to internal conflict that I honestly can recall are Gema's and my own experience in getting access to the field as described in Chapter 3. What is surprising, or not, is that both incidences involved the same person. Three important issues I want to stress here: First, I believe, based on my experience and those of my informants, that there has been a subtle qualitative change in the way that power and decision-making works in the AECC, in part because members mastered the skill of agreeing and then did whatever they thought it was more convenient, and in part because it is never late to learn to accept criticism. Second, this is a topic too sensitive and confidential for inquiry in this thesis and as such I will very briefly provide a small example based on information which I am allow to publish. Third, AECC Carolina is an autonomous "social system" with its own characteristics, problems and dynamics. Therefore, it cannot be generalised in any direct way from how AECC Carolina resolved its tensions *at that time* to other regional AECCs or the AECC as a whole.

Gema, who had cancer four years ago, used to come to the AECC regularly to chat with other members, volunteers, Pedro and Noelia. Given that she was energetic and skilled she even had lead some social activities. Yet, despite the fact that she had a fantastic relationship with many of the members who went to the AECC regularly, she told me that she had gradually resigned from all activities. The main reason were irreconcilable differences with an influential member of AECC Carolina's steering committee who had a very strong personality and exerted a strong hold over members', the process of decision making and social activities. As I said, this information did not come as a surprise given that my bruises from when I was trying to get access to the field were still very sore.

According to my own experience, conversations with Gema and fragments of private conversations off record, differences and tensions arose mainly as a consequence of a combination of strong personalities and differing understandings of how social power should be used by managerial positions. The combination of irreconcilable

differences and strong personalities created a very tense environment every time they met in the association. There is not doubt that the member of the steering committee wanted the best for the AECC, yet in Gema's words she "was frustrated and indignant by her reluctance to accept any feedback or criticisms on how undemocratically she was managing *la Asociación*". Informally, many members recognised the problem, but *la Asociación* as a whole did little to mediate between the two. My feeling is that some members and volunteers felt the need to exercise caution, after all they liked to come to the AECC and they did not want to face harsh confrontations in public. Gema choose to leave the social activities of the AECC in protest. Even so, I still find some reasons to admire the aforementioned person for her passion and commitment to the AECC.

Having explained this I considered myself very fortunate that women like Cayetana, Blanca and Gema accepted to participate. I will explain their justification in what follows. For the most part, participating in the life of the AECC was a matter of "being fair" (Blackstone 2004). As explained before, there are different levels of participation which can be read as ways of "expressing gratitude" or "being fair" for the support received. Becoming a member and paying membership fees which helped to finance *la Asociación* was the most basic level. All the women without exception, and even some of their relatives and friends, became AECC members after a few weeks of entering *la Asociación*. Volunteering was another way of participating. Some women participated as testimonial volunteers, sharing their experiences at the hospitals. They also worked in the headquarters of the AECC when Noelia required them because she had an "acute case" (usually an extremely negative or upset patient who did not accept the illness or the inevitability of its social consequences, as I will explain in the next chapter). Some other women collaborated through offering their time organizing activities or giving a hand with administrative duties.

One of the main reasons why women accepted to be interviewed was because the AECC had invited them. More concretely, because Noelia and Pedro had encouraged them to participate in my research. The interview was women's way to "pay off" a moral debt to *la Asociación*. A common desire to help other women in the same situation was another major reason why women participated in my research, as well as acted as testimonial volunteers. The dominant discourse around participation was what Blackstone (2004: 357) has coined the "rhetoric of fairness". This should be understood in terms of the philosophy of the gift proposed by Mauss (1971) explained in Chapter 3.

Returning to the example of Cayetana, the gift of receiving information and support from the AECC demanded a similar gift from her. For her, her best gift to *la Asociación* was her participation in the interview by sharing her more intimate experiences of breast cancer in the hope that this thesis creates change.

As we have seen, for many women the AECC served as a conscious community space through the physical act of gathering and sharing experiences of illness with other cancer patients. It was precisely this conscious awareness of their need to share burdens, support each other and speak out about cancer what made *la Asociación* effectively, and affectingly, experienced as a political social support. However, the AECC was not a naturally empowering space for all the members, and it could be a medium for affirming power relationships or reminding women's of their precarious health.

5.3.2. Street Therapy

While the support of the family and close kin is the most obvious form of social support, and can have positive immediate health consequences, my findings highlight the healing nature of *la calle* (the street) upon the physical and mental health of women. The tone for the profound importance of *la calle* in women's health was reflected in the expression "the street is my best therapy" (*la calle es mi mejor terapia*). In this section I identify and reflect upon some of the qualities of the street and significant factors that contribute to women's well being. Looking at the different ways in which women define, use and appropriate the street, I will also briefly examine how the concept of street therapy and its social functions carves an epistemological space for new definitions and analysis of the street and women's use of space.

Simply from being Spanish and having grown up in a small village in rural Spain, I recognise the power of *la calle* to cheer me up and *despejarme la cabeza* (clear my head). I became fully aware of its power when I moved to the north of England seven years ago. Ceaseless rain, infinite winter darkness and deserted streets trapped me at home during the evenings, as well as many weekends, making me feel grumpy and suffer from migraines.

I felt (and still think) that fresh air, sun, and interaction with people have the power to blow away my concerns, and provide the relaxation necessary for a healthy night's

sleep⁴². Moreover, the use of this idiom is very widespread in Spain, as attested by the Royal Spanish Academy. But, to be honest, it never occurred to me that the street could have this kind of therapeutic power in someone suffering from something as serious as breast cancer. At the time of my pilot study, although this belief made perfect sense for me, I thought it was mainly because my informants were from rural areas. As my PhD fieldwork progressed, mainly interviewing women from urban areas, it struck me that the therapeutic power of the street actually emerged in one way or another in the majority of the interviews.

In my research, two important points should be stressed when writing about the street in the context of illness: First, for women, *ir a la calle* (go to the street) for therapeutic purposes demanded meeting or going out with someone. This someone was not necessarily a relative, but it could be a friend, an acquaintance, a neighbour, or even a close colleague from work. This finding confirms Durán's (2008: 150) argument which states that social bonds not based on consanguinity and kinship are increasingly important in contemporary Spain. From her point of view, the street *y la plaza* (the square) are "not merely channels for transit and transportation, they can become in crucial spaces to enable and foster further these social bonds and coexistence" (Durán 2008: 125). This is therefore the main reason why "the street" deserves a place in its own right within the category of social network.

Secondly, in contrast to some other studies (e.g. Newcomb 2006) the *street* not only refers to the exterior of buildings, it refers to going anywhere outside the house. This includes interior spaces and private spaces too: from the park or the open-air swimming pool to shops, coffee shops, the AECC, the cinema, concerts, walking, the church, carnival parties, weddings, buying the newspaper, friends' houses, or even sitting on the porch or front doorstep of their houses or their neighbours'⁴³. I must stress here that although the notion of the street involves going out the home, women's choices were not universal. These choices depended on women's personal experiences with a

⁴²It is worth noting that David Gilmore's work on gossip in the south of Spain three decades ago support my arguments about street medicine. Although his analysis goes in a direction different from mine, his work hints at the therapeutic role of the street. Going to the street was presented by his informants as a need to "take some sun", "take fresh air", "socialize" or be part of the community (1978: 91). Yet, when reading David Gilmore's work and my work we should be wary about equating the therapeutic role of the street solely with the possibility of gossip.

⁴³Sitting on one's porch or front doorstep or on the neighbours' seemed to be more a phenomenon of small towns. Yet, chatting in the street is a common custom in the cities too.

particular space. They were also influenced by the qualities of determination and indetermination of the street (which I will explain later).

Despite Spain's positive reputation of a lively culture of street partying and socializing⁴⁴, it is interesting to note that much of the research on the street has focused on its negative aspects. One of these interpretations describes the street as "place" of social control where the individual is forever trapped by the public gaze (Peattie 1968: 54-70). However, some of these analyses are short-sighted since they are based on the anthropological fiction concerning the exotic traditional and rural Spain. Dominant discourses focused on rumour, gossip (Gilmore 1978) and nicknaming (Barrett 1978), viewing such practices as mechanisms to ensure a high level of social "order". However, women's experiences showed that this public gaze was not always negative or ubiquitous.

Another negative reading of the street represents it as "the territory of the big bad wolf which can devour us [women]" (Cedeño Pérez 2009a). Interestingly, according to Cedeño Pérez (2009b) and del Valle (1996) the street is not dangerous because of its physical attributes (e.g. it is inhabited by strangers with dubious intentions), but because women have been socialized to feel unsafe, unease and paranoid within the public space. That such an ideology is so persistent and resilient nowadays reveals the assumption that women's place is at home. In other words, that women should not be in the street at certain times unless "they are looking for something"⁴⁵. Delgado (2007 in Cedeño Pérez 2009a) notes that the expression "a man of the street" has a different connotation to the expression "a woman of the street" (*mujer de la calle*). A woman of the street is a "happy woman" or a prostitute. Quite the opposite, the expression "a man of the street" denotes the man's "natural" relationship with the public sphere, and correspondingly man's with politics. Implicit here is the idea that the very fact of being involved with public affairs enables freedom and pleasure. Yet, it is assumed that only men, and bad women or prostitutes, are entitled to enjoy freedom (from the domestic responsibilities) and (sexual) pleasure.

Linked to this is the need to clarify and earlier, negative reference made in Chapter 4 to being left in the street as a sign of abandonment. Although I could not find the

⁴⁴See for example Labanyi's edited volume (2002).

⁴⁵ See Porroche-Escudero (2007) for a detailed discussion on public attitudes to women's use of some public spaces at certain times during the day. See also Frohman (1995)

origins of the expression, building on Teresa del Valle's work (1996) I would argue that the difference between the two expressions is that "going to the street" is a temporally, time bound and voluntary action. The person has the possibility to return to somewhere. In this situation "there is not a breaking off with the responsibilities or activities of home" (del Vale 1996: 10). On the contrary, *quedarse en la calle* is a forced and passive situation which conveys a sense of permanence and a lack of security provided by home. The Royal Spanish Academy Dictionary defines this expression as "expel someone from his/her house, job or responsibilities". Whereas going to the street is voluntary and is a signifier of freedom and healthiness, to be left in the street is associated with the structural violence that surrounds homelessness including "attacks, robberies, violence, illnesses...aggravated by dirt and cold" (Durán, 2008: 97)

Why then, do so many women recognize and seek going to the street for therapeutic reasons? I believe the answer lies in a combination of the several factors: First, the tangible benefits of receiving sunlight and gentle exercising of the body. Second, significant cultural understandings about the street. Third, some qualities of the street including its determination and indetermination. As I mentioned above, a particularly important aspect of the street is its social function as a social network. My work on gender violence makes clear that my intention is not to deny the fact that the street has some negative qualities that could be disempowering, especially for women. On the contrary, it is precisely because I consider the issue so important that I believe it is important to acknowledge that the street has healing capacities too so we can work to promote these possibilities qualities in benefit of patients' well being. Also, I do not maintain that the street cures cancer or is the panacea for all the physical problems triggered by cancer, but it does take an important role in improving the physical and psychological well-being for many breast cancer patients. The issue is important and should not be considered trivial.

Let me illustrate these points by first explaining some cultural beliefs about the street which evoke the emotional and physical benefits attributed to it. Then, I will explain the qualities of indetermination and determination which complicate the literature on the public gaze and its disempowering effects. The conclusion considers how the street can be a "bridge space" (Valle 1996) where women consciously appropriate the street for their own benefit.

Geographer Yi Fu Tuan (1977: 6 in Hayden 1995: 16) notes that “individual sense of place is both a biological response to the surrounding physical environment and a cultural creation”. To understand this point, and hence the therapeutic nature of the street, Manuel Delgado Ruíz (2001) argues that we have to turn our attention to the cultural meanings of the street in Spain. In his essay *Elogio del Afuera* (‘In praise of outside’) (2005) he elegantly argues that *la calle* is an integral part of Spanish social life. He proposes that the street is an extension of the person. The street is the zone where politics, religion and *fiesta* are practiced and contested by *all* citizens, regardless of gender, on an almost every day basis (see also García-Ramón, Ortíz & Prats 2004)

Street life goes from individual practices such as *tapear* (eating tapas) or talk in the streets with neighbours (Gilmore 1978) to community practices such as *charangas* (brass bands), *corrida* (bullfighting) “processions, parades, marches, demonstrations, gymkhanas, popular races, popular meals, celebration of sport victories, *correfocs* (literally “fire-runs”), but also riots, barricades and clashes with the police” (Delgado Ruíz 2001: 143). It is for these reasons that Delgado Ruíz (2000) argues that spatial preferences are never fortuitous choices. It is its symbolic connexion to *fiesta*, leisure, socialization and space of public (political) speaking that the street contributes to women’s well-being. This explains why the experience of street therapy is personal and space bound.

Many of the idioms surrounding *calle* are connected to a sense of “freedom”. It is worth noting here that the fifth meaning of street found in the Royal Spanish Academy Dictionary contrasts street “to prison, detention, etc, freedom (state of the person who is not a prisoner)”. This immediately enables us to make sense of Delgado’s remarks concerning the association between the expression *mujer de la calle* and freedom.

Similar to the beliefs I grew up with, it was commonly conveyed by women that *ir a la calle* helped them to alleviate stress and reduce anxiety by distracting them from their worries and pain. It also allowed “clarity in thinking” by sharing and discussing concerns or fears with neighbours or friends. Very importantly, it helped patients to gain physical strength too. This idea of street medicine was enthusiastically described by Melissa, a well-educated cancer survivor in her mid-fifties:

This is my theory: when I feel very ill but I don't know whether I am ill or just very scared, I go to the street. If *en la calle* I still feel very ill I go to the doctor. If it goes away (*se me pasa*), it was fear (laughs).

Melissa's experience proves Yi-Fu Tuan's above-mentioned words. To put it simply, "sensitivity to the street is set up through the body" (Delgado Ruíz 2006: 123). Strange as it may seem for someone who does not belong to the Spanish culture, the healing nature of the street was intertwined with an embodied factual biological response of getting better, or at the very least feeling better, together with cultural embodied beliefs about the street. On one level, going to the street may have made women feel better by receiving sunlight essential for their mood and vitamin D⁴⁶. It helped to stretch numb and stiff joints, as well as preventing further loss of muscle mass as a consequence of convalescence and cancer treatments. It allowed women to gain a sense of healthiness which their illness had taken away. The street also allowed them to be distracted from negative thoughts about cancer and their constraining gender roles at home. On another level, women felt better because going to the street allowed them to reconnect with their social environment. In other words, it allowed them to regain their social role as members of the community. In sum, going to the street was an active and conscious mechanism to recover a situation of normalcy through being physically active and through the gaze of others.

All this easily hints at the positive connection between public gaze and healing made feasible by one of the attributes of the street, its determination. I deliberately use this term to convey a quality opposite to what Delgado Ruíz (2005) calls "indetermination". According to Delgado, the anonymity granted by indetermination of the street enables the individual to be invisible and to escape the control of the public gaze (see also Cerdeño Pérez 2009c). Thus, by opposition, determination denotes the capacity of the street to visibilize the individual and in doing so gives him/her a social identity. The influence of this attribute seemed stronger in villages, towns and *barrios* although urban cities also had it. The recognition of this quality has long attracted the attention of anthropologists undertaking research in Spain, being the example of gossip.

For example, women's decision to break out of conventions of invisibility surrounding cancer may have been prompted by the fact that few things can remain

⁴⁶ Vitamin D is essential for bone and musculoskeletal health (Sinclair 2006: 202).

private to the public gaze. This was beautifully encapsulated in the reasoning “Once everybody knows, what can you hide?” A frequent cited example comes from the use of wigs, make up or other “artefacts” (Lorde 1997). For instance, the fact that the public gaze disclosed that they were sick, made them feel that they looked like “buffoons” with the artefacts. To certain extent these feelings seemed more prominent in villages or towns given where women were known by the community members, but these feelings were also described in big cities, especially in the *barrio*. In these accounts, “normative constraints” which promotes concealment of the illness as described in Chapter 2 and women’s “comfort”⁴⁷ were contrasted.

I am able to illustrate this point with material gathered during my MA fieldwork. The following quotation is an extract from a fascinating discussion regarding the unrealistic imperative to look normal and feminine. It indicates how the indiscretion of the street, with its gossip and interpersonal relations, liberated women from normative constraints which in turn, helped to manage their illness.

- Maria: They recommend you make up a bit. But good heavens, some of them follow the instructions precisely!. I thought...
- Sara: The buffoons!
- Maria: Barbie.
- Everyone: Laughs.
- Pepita: I wore comfortable clothes.
- Sara: Me too.
- Maria: Yes, I wore flip-flops and a scarf.
- Sonia: True, you look for comfort in those days.
- Maria: Good heavens, we don’t have to pretend! It is true, I tried to Look good, but it is not necessary to disguise ourselves and conceal we are sick. Of course, everybody knows here. Perhaps no-one knows in the city.
- Lidia: Not even the neighbours know. No-one knows each other.

⁴⁷ For example, discomfort in wearing a wig was commonly reported as a physical complaint for the women. The best way women found to describe to me how it felt wearing a wig was to define it as like wearing a “wool hat in summer”. We should take into account that treatment for breast cancer lasts at least one year, therefore, all the women reported going through the “scorching” Spanish summer. By scorching they meant a summer in which temperatures can reach easily 40°C.

Sonia: You must feel very lonely and isolated there.

Lidia: Yes, here is warmer. Better.

I must stress that although this data is from a focus group facilitated in a rural area, not significant differences by geographical location were found in women's experiences about the qualities of the determination of street.

The link between the determination of the street and women's well being is not inexorable though and cancer patients do not look always for the comfort of visibility. Indeed, some women may actively resist it. Here is where the "indetermination" of the street explained earlier becomes powerful to exercise agency. This in turn illustrates how the concept of street therapy is space-bounded and also depends on women's personal experiences. In other words, each woman embodied perception of street therapy is inseparable from her personal experiences with a certain place, but particularly, the specific context which includes time of the day and type of social networks they are with.

For example, for some women there were days, or moments in the day, that had no desire at all to be "visible". Some other women sought anonymity always. They wanted to enjoy the pleasures of the street like meeting with friends, having sunlight, or walking, while keeping away from the public knowledge their presence and/or status as patients. In fact, in these circumstances one of the biggest pleasures was anonymity which allowed them to take a "break" from the sick role. The prospects of "putting a brave face for everybody else" (Wilkinson 2001: 271) or repeating the same updates about their health over and over again to their friends, neighbours and acquaintances, were dreadful ones. The act of retelling how they felt could be extremely painful because it reminded them of their miserable health. It could be extremely tiring too, in particular, because it took away time from the person(s) who was accompanying them.

In these cases, the indetermination of the street encouraged women to use "artefacts" (Lorde 1997) like scarves, wigs or make up to "normalise" their identities in an attempt to "enjoy the right to indifference, to not being taken into account. Being just what they are: bodies that move to new pastures, without origin, without history, without labels" (Cedeño Pérez 2009b). Here we have seen how both qualities are fluid and contextual: they are individual, time and space-bounded. The same quality which is the basis for women's comfort, safety and relax can be disempowering at other times.

Whenever possible women tried to juggle with these qualities to turn them to their own benefit.

To conclude, elaborating on the pathfinding work of Teresa del valle (1996) and Montón Subías (2000) on the relationship between gender and space, the concept of street therapy provides an enlightening case study to challenge the presumed maleness of the public sphere and corresponding absence of women in the street. They argue forcefully that the mainstream view of women as belonging to the domestic sphere is the result of an androcentric bias based on stereotypes about women as reproducers. Link to this, Montón Subías' (2000) and Guerra Palmero's (1999) posit that this bias is also because what is regarded as public is defined by men's activities. The concept of street therapy described by women's embodied experiences shows how the street can be defined as a "bridge space" (Valle 1996) which enables women's agency. Women do use the public space and its appropriation is far from passive or solely as an extension of their domestic roles, but very much active through their agency.

Nonetheless, although health professionals recognize the benefits of *salir a la calle* as an important part of the process of recovering health, both the AECC and oncologist Joaquina Lozano warn us that Spanish cultural emphasis on taking the patient to the street may be detrimental in some occasions. Women's weakness and side-effects are not always visible in the body. This, coupled with ignorance about how treatments impact on women's body and mind, means that family, friends and neighbours can push women too hard despite their weakness. Martínez Lozano and Martínez Zaragoza (2003) explain it thus:

(In Spain) there is the bad custom of thinking that we have to take the patient to the street to avoid him/her from feeling depressed at home. But it can be an error. Just the very act of trying to go out or even moving with low immune defences as a consequence of treatments can be a "calvary". Moreover, it can contribute to the debilitation of cells, thus delaying recovery. We should not force any cancer patient: when s/he feels strong enough s/he would be able to go out and work as much as s/he wants.

5.4. The Constraining Factors of Social Networks

Being from a rural Spanish village, and part of an extended network of family, friends and neighbours, one of the most important lessons my research has taught me is that romantic ideas about social networks may limit my ability to recognize that they are also a complex site for conflicting values and tensions (Hartmann 1987). This is particularly salient in long-term disabling illnesses such as breast cancer, as it may burn out carers, patients and resources.

As I mentioned above, the Spanish model of family is often portrayed as a site which provides the most important source of affection and care for the ill. Yet, some feminists argue that this vision obscures diverse interests and conflicts which occur within the family in ways which are socially and culturally gendered (Hartmann 1987).

5.4.1. Tensions between the Role of Mother and of Patient

In the stories of my women informants with children, the conflicts between maternal responsibilities and their role as patient was an issue which caused enormous distress, sadness, feelings of failure as mothers, and subsequent guilt. This distress in many occasions was twice as obvious when the children were small or were in their teens.

In line with previous writing on women and cancer (see for example Picardie 1998), I found out that dying was the foremost concern of women. Women with dependent children worried about death because it meant that their children would not have a mother to provide physical care and emotional nurturing. Many of them, although they did not question their partners' love for their children, were uncertain about their partners' skills for mothering. In my research, mothering meant the ability to nurture, care, navigate the complexities of educating children, manage the complexities of social networks (e.g. family, doctors, teachers, extra-curricular activities, birthday parties) as well as the logistics of the home (e.g. housework, maintenance, repairs, bills). The over-arching implications of the responsibilities of mothering were reflected by Maribel:

Look, I started to break down after my husband failed me, I mean with the housework and the like. I have wanted to live this as if nothing bothers me. I didn't want to worry about the future, but enjoy the present. I wanted to think that if something happened everything would be OK, my daughters would manage. But right now, when I see that my husband is not able to carry 70% of

the burden worries me. If this happens now, if something happens to me he won't be able to carry the 100%. What would become of my daughters? This has been *durísimo, durísimo* (extremely hard).

Some mothers, like for example Maribel, Che, Marisa, Alejandra or Francisca, saw themselves as irreplaceable to the extent that the reality of death was foreseen as a sort of orphan-hood for their children. This was especially true when children were dependent on them. Although Marisa had a difficult divorce and poor relationship with her ex-husband, in recalling her feelings after diagnosis, she articulated the sentiments of many women regardless of their marital status:

I don't know... it was a feeling... I remember very well thinking that night 'Jesus! If I die, Bruno (her son) will have to go and live with his father!. Damn, I can't do that to my son'.

Women who were the main breadwinner, or with economic difficulties had the additional concern of not being able to provide financially for their children. As we saw with the case studies of Che or Amalia, an urgency to go back to work even before they were fully recovered was not a free, autonomous choice. It was an obligation. As said by women, this seemingly self-evident desperation to bring money home was not understood by many health professionals and other social networks, who might accuse them of being irresponsible and more interested in their careers than in their health or family members. In the following fragment, ideas of appropriate "illness behavior" (Helman 1994:108-110), fuelled by gendered guilt, surface in Che's words:

How can I explain to my oncologist that my defenses are low? How? How can I explain to him that I have business and that I think I will have to go back to work before I expected?

While in Spain there is a considerable general interest in promoting *una vida normal* (a normal life) among cancer patients, my informants were aware that many health professionals could interpret returning to work while on treatment as a kind of irresponsible behaviour. Like in Medieval England (Thomas 1997: 16), and as sketched

by Parson in his sick role theory, it is still thought, both morally and medically, that patients have the obligation to do everything possible to recover the health: from compliance with the treatments to convalescence (Roche Farma 2001:25). Aronowitz (2001: 375) observes in his history of discourses on cancer prevention that controlling cancer “in time was linked to norms for maternal, marital, household, and civic responsibilities”.

Women were advised that convalescence following surgery, radiotherapy, and, in particular, chemotherapy, were crucial to recovering their health and strength. Thus, they should avoid “unnecessary” excessive effort. This emphasis has a biomedical explanation. White blood cells are essential for the immune system for two main reasons: because they can recognize some cells as malignant and kill them, and because they protect the body from infections (Cancer Research UK 2008). However, white blood cells are produced much more slowly during cancer than in normal circumstances as a consequence of treatments. On top of that, cell growth is negatively affected by physical exertion (Roche Farma 2001: 25). Subsequently, infection problems are more likely among those women whose immune systems are weakened (which in biomedical terms is called having a low cell count). This situation may lead to delays in administering chemotherapy. Although it is hard to measure whether returning to work actually prematurely adds to the problem, it was nonetheless a great cause for concern and guilt for Che and other women who felt they urgently needed to, as they know that chemotherapy is very effective if the disease is caught at an early stage, but decreases in efficacy if disease has spread.

Given this context, going back to work prematurely “results in a certain shame about the disease, because it implies that individual women are responsible for their illness” (Yadlon 1997: 661). Thus mothers fail twice to accomplish both the obligations of the sick role in terms of their ability to take care of themselves, and their financial or care obligations to their family. In the face of this dilemma, the argument of these women was that staying at home in order to get rest also compromised seriously their children’s well-being since they would not be able to make ends meet for their living.

The harshness and demands of treatment were experienced as another source of great stress for women with children. As I mentioned in Chapter 2, treatment may affect social relationships with children and family. It also changes domestic and mothering arrangements because it weakens women’s bodies and mental faculties. In many

occasions women found difficult, if not “inhuman”, to conform to the role of cheerful, playful “good mothers, with ostensibly selfless devotion” (Blum 2007: 202). Yet, all the women acknowledged that they had put on a “brave face” (Wilkinson 2001: 271) at some point in order to minimize their children’s or family’s concerns. Penélope, a 56-year-old married woman with one son, underlines the suffering of putting on a “brave face”:

Penélope: I mean, I used to put the mask on in the street as if nothing was happening. Normal, happy... but when I arrived at home (sigh), I collapsed.

Ana: Did you put on the mask at home?

Penélope: Sometimes too. So they didn’t suffer. Just when I was alone is when I used to breakdown and cry all the time.

Another clear example of the “mask” widely noted in the literature on breast cancer and discussed earlier was when women used a wig or scarves in order to minimize the visual impact of baldness (see Harcourt 2008; Rosman 2004; Browall et al. 2006), even though many women found it very itchy, suffocating, unnatural, or fake.

Although with far more resources than Che, Maribel, a school teacher married to an engineer and mother of two small daughters aged 3 and 5, presented the best case study for illustrating the conflicting relationship between the traditional idea of motherhood and the sick role. Maribel was very conscious of the importance of convalescence to recover quickly from the effects of treatments in order to resume her life. Yet, she was distressed because she knew her rest would be seriously compromised by the demands of mothering. When I met Maribel she was receiving chemotherapy. Anticipating its side-effects, she and her husband decided that the children would live with Maribel’s parents for those weeks during which she had to receive chemotherapy. This decision was traumatic because it was felt by Maribel as being an abandonment of her children. Moreover, although she wanted to see her daughters every day, her account revealed intense guilt when she acknowledged relief when the visit time was over.

They give me chemo on Fridays and I spent the weekend going from bed to sofa and from sofa to bed. My husband cooks, he does everything. And if I have enough strength I like to go to church. Sometimes I go to see my daughters or

they [her parents] bring them home and I spend an hour or so with them, because if they leave them for two hours I start feeling like a bad mother because I am wishing they would come to pick the girls up.

Both Che and Maribel were aware that they had transgressed the norms of “good” motherhood, but at the same time they rejected the widespread cultural suspicion that they were “bad” mothers. After struggling to resolve the contradiction posed by their roles as mothers and their role as patients, they considered that they had no other choice. Their feeling was summarized in the belief that a mother absent for some time was better than a dead mother.

Che and Maribel’s decisions illustrate what Sulik (2007) defines as “the balancing act” (Chapter 2). Their “subversive” behaviour of leaving their children is explicable when understood through the balancing act. For them, the process of negotiating motherhood and the sick role was as follows: if they wanted to be *a* mother, they had to be away from the stress of mothering to take care of themselves in order to fight off the cancer. On the contrary, if they resumed their role as mothers, recovery would be much slower, jeopardizing the efficacy of treatments and increasing the probability of the disease spreading, compromising therefore their lives and their children’s upbringing.

As we have seen, the demands of cancer treatments pose a difficult case that defies “traditional” definitions of motherhood, and challenges in turn Parsons’ gender-blind sick role theory. Just as women are mothers, or just as women are breadwinners, these roles seem neither to allow them enjoyment of the benefits of the sick role nor to accomplish its obligations. Before going to the next section, it is important to stress again that women who had finished their treatments, as well as those who were survivors were not totally liberated from the gendered pressures to hide their fears, for example of recurrence. A common feeling is that the longer they had finished their treatments, the harder, or sometimes impossible, they found to discuss with their family their fears of recurrence or pain. There seems to be a taken for granted assumption that fears of recurrence, pain or side effects are only normal for some time after treatments have finished, but some family members may regard them as irrational when they do not disappear with time. Women demanded that family members, health professionals, social networks and the social care system recognise the late effects of cancer. This

issue will arise again in the next section and in the next chapter when I present women's experiences of ALND and sexuality.

5.4.2. Tensions between the Role of Wife and of Patient

Even among those women who had supportive partners and families, there was a sort of agreement in my data that the “tyrannies” of housework were a cause of stress and tension within the family, especially when women were actively receiving treatments (e.g. surgery, chemotherapy or radiotherapy). As I explained before, women were well aware that treatments would weaken their bodies. Symptoms such as body pain, vomiting, exhaustion, cold or headaches were the norm for many women during, and often many weeks after finishing, treatments. Given these circumstances, simply the psychological burden of having to run the house as soon as they were back from hospital made housework appear more arduous than usual. Maribel, who was receiving chemotherapy at the time of the interview articulates these feelings well:

I have to clean the house, but I must manage my energy. Perhaps I am only able to clean one room a day because I don't have any strength left. Sometimes cleaning a room can take me up to three hours! The other day I was thinking about this. I thought: 'how can this be possible? If this is so little!' But it is that I start the day being tired already. I don't stop, I do lots of things.... but they are never finished (Maribel).

Depending on the intensity of the side effects of treatments, as well as of each woman's personal circumstances, housework was described as unbearable. It was seen as the main cause for which women neglected themselves and their need to rest. This was particularly so in the cases of women with small children like Maribel or Alejandra; women with dependents like Blanca who had to take care of their orphan nephews; women without an extended *and* close social network of relatives, friends and neighbours to whom ask for help like Rosario; and those women with lower economic resources who could not afford either sick leave or a cleaner to give a hand like Amalia (see Hartmann 1987; Achat et al. 1998). On the contrary, better-off women like Melissa or Rosa Mary could hire someone to help them with the housework during treatments.

Housework was very often described as the root cause of feelings of sadness, guilt, anger and disappointment with their partners and grown-up children. A few women made a strong association between the gendered nature of housework and their inability to accomplish the sick role. They complained that men would have more “quality” time for convalescence and rest because they were free from domestic responsibilities. They implied that husbands did not have to make any physical effort, but they did not have to worry about mothering either. That is to say, “who takes care of the children or whether there are clean clothes ready for the next day. Someone else is doing that work” (Jackson 1997: 330). In the following fragment Julia emphasises her gendered feelings of guilt about not being able to accomplish her responsibilities as a housewife. Her insights demonstrate that she was aware that she was taking less care of herself than of her family despite her weakened health:

He [her husband] saw I couldn't do anything and he told me not to worry about it, but I suffered. I worried about the others but I didn't worry about myself (sobs). What do you think? It was 11am, it was 12pm and I remember thinking: 'Oh my Goodness, Pedro is going to come back and there isn't any lunch ready'. At 1pm I couldn't move: 'Oh my God, I can't do anything. I am going to try to do something'. But I could do nothing. Nothing. That was unbearable for me! I was consumed with anger.

Family expectations that women will resume work immediately after finishing treatments hurt them because housework was not being taken seriously, but was taken for granted. Maribel's account illustrates this situation very well:

I found his selfishness in this [housework]. I do think that if he'd been ill he'd have been the spoilt boy (*el niño mimado*), but I don't feel I'm the spoilt girl. In a month or so I'll tell him: “we already had problems before because of the housework. What have you done since you started working again [after holidays and her diagnosis]? You do much fewer things that last year”. I already mentioned it slightly but he said that I have more time than him because I am at home. I told him “I'm not on sabbatical. I'm on sick leave! But you don't understand the difference”. Then they give me the chemo, he goes to work and

he doesn't bother to think what he'll eat. Perhaps I should be cleverer so that if he wants to eat something when he comes back home and the food is not ready he will have to open a tin... But I gain strength and I end up doing things yet crying: "but why he is not able to see these things?" These things do hurt. But what happens is that I see that he loves me and he supports me a lot. But you realize that if they [men] were ill the situation would be totally different. I don't know whether it is related to gender or not but I think that they wouldn't make any effort if they were not able to. But women are just the opposite, we do things in advance (*las mujeres nos adelantamos*).

While for example vomiting is the extreme expression of cancer treatment symptoms which grant a certificate of illness (see Chapter 2) and "exempt" women from normal responsibilities, those less tangible side effects such as headaches, cold or tiredness are more likely to remain unseen. In this manner, family members may not take women's convalescence seriously as they believe that women are "doing fine". This was well-illustrated when Maribel's husband excused his lack of domestic involvement because Maribel was spending more time at home now. Maribel had to reproach him that she was not on holiday but on sick leave.

Similarly, for those patients who do not receive chemotherapy treatment, being discharged from the hospital was closely linked with being well. Cancer and chemotherapy are knitted together in the collective imagery of cancer. In other words, cancer is associated with the side-effects of chemotherapy. For example, being discharged from the hospital without prescriptions for chemotherapy or radiotherapy was understood by social networks as a clear marker that cancer had been eradicated, and that the patient was not suffering any further discomfort. This belief was not necessarily shared by women though. Rosario, a 66-year-old single woman, living in an old people's home, and having a rather "formal" relationship with her brothers and sisters described this situation eloquently:

I think my family supported me. I mean, supported me when they came to visit me in the hospital. But I think they were not aware of the consequences of [ALND] surgery. For example, one of my sisters told me to go to her place for meals. I looked for a service which could bring me meals at home but I was told

that doctors would need to assess my situation in a meeting, because there was a service here in the city but it would take time and I told them: “I need it now!” Then my sister told me: “you can easily come to my home for meals”. Indeed, the same day I was discharged from hospital they came to pick me up, took me to their place and had dinner... but they did not realize how many limitations I had. More or less they thought that [cancer] had been taken away the same as when you get rid of a blackhead! And after the dinner they drove me home. By that time I had to switch the heater on and I found out that I couldn’t because I had to press two buttons at the same time! But I didn’t ask for more help... I went to my sister’s for a while but then I stayed at home. I didn’t make my bed for a long time (laughs) because it was very big and I couldn’t. So that was what happened.

As I have mentioned countless times, the imagery of breast cancer patients’ suffering emphasises and plays upon an association with mastectomy and other visible effects of disease (e.g. baldness). Thus certain “invisible” side effects of surgery like ALND in the case of Rosario, exhaustion or cancer fatigue, or emotional distress, were not part of the collective imaginary on cancer suffering, are most often ignored by those who surround breast cancer patients. Sadly, I found that this area of concern was even more acute for survivors with sequels. Indeed, very little research has looked at these issues affecting breast cancer survivors. Failure to acknowledge the seriousness of their health problems during and *after* treatment was described as pervasive and alienating and affected their quality of life. I will describe these feelings further in the next chapter.

5.4.3. Trapped Men: The Mute Husband (el Marido Mudo)

When talking about the relationship with their male partners, there was a common theme that a lot of women spontaneously presented as being troublesome. While many husbands may be very supportive in some aspects like for example, listening, accompanying the woman to the treatments or helping with the domestic chores, women complained about men’s lack of ability to empathize with their emotional needs. This inability represents what a few women termed the “mute husband” (*el marido mudo*). This expression was not used to convey a generalized idea that men are emotionally absent from the relationship. On the contrary, according to most women who were

married or in steady relationships (17 women out of 21 informants) their partners showed concern about their health. There was a striking consistency in the way in which showing concern was described and experienced by women. In agreement with previous research (e.g. Pratt and Mason 1894), common words to describe “this involvement” were: listening, having a caring attitude, showing empathy, understanding, offering attention or love. However, it is important to highlight that the expression “the mute husband” was used specifically to connote a feeling of aloofness or remoteness caused by an inability in men to speak *about one’s own* feelings.

The issue of the mute husband who does not speak of his feelings was never articulated more strongly than in the story of Julia. Her story differs from the others as she stresses several times throughout the interview her husband’s inability to verbalize emotions. It is interesting to note that Julia pointed out the fact that her husband “was a good husband” who showed concern for her: he listened, was understanding of her situation, and, during the worst phase of the treatment, contributed to the domestic chores. Yet, the lack of discussion about feelings was described as an important cause of feelings of incomprehension and aloofness:

It is that my husband doesn’t say anything. He shuts his mouth. He doesn’t give his opinion. He is quiet and has them [emotions] inside. This is not the way it should be, we should share things... They [men] should learn to talk! It is not that they don’t talk but... For example, he came to the hospital. The doctor explained the process and all the things but... I would have liked him to...I had to deal with my illness by myself. Perhaps he accepted it [cancer] differently... how could I explain it? He suffered it in a different way.

Julia brings into sharp focus some important issues that should be taken into account when researching the effects breast cancer on women’s heterosexual relationships. Like Julia, I did not think that the mute husband was the result of men’s insensitive nature. As was outlined in Chapter 2, I thought it was rather a reflection of Spanish men’s social gendered behaviour which in this case was pathogenic (Helman 1994: 163). In Bourdieu’s view (1999) traditional definitions of masculinities portray men as active, dominant, strong, sexual and able to control emotions. Since childhood, boys are getting the message that certain emotions such as feeling shame, pain, insecurity or fear are not

appropriate for men and should therefore remain private (Béjar 2004). Although, this pathogenic gender behaviour is customary in Spain, it should not be surprising that older men found more difficult to speak of their fears and emotions with their wives. As I will describe in the next chapter, older men, like older women, were socialized in their youth by a regimen which “glorificated masculinity as the pillar that sustained the regimen” (Pérez-Sánchez 2007)

As we saw above, Julia was aware that her husband’s failure to communicate his emotions was not because he did not love her, but because he had never “learned to talk!” According to Julia, and Noelia, the psychologist of the AECC, Julia’s husband’s suffering was aggravated by “the ways men feel obliged to conceptualise and perform masculinity [which] make it difficult for them to behave in ways that are empowering for women or even that would seem to be useful for men” (Harris 2006: 51). Under these circumstances, Cecil Helman (1994: 163) would argue that the “mute husband” is a “disease of male social gender”. Maribel illustrates this well when she recalled the first time she saw her husband crying after the doctor told her that she did not have many chances to survive cancer:

I think that in order to survive this illness it’s very important to have the energy to fight against it. If they take away your hope, they take your life. Therefore, he [the doctor] was the one who broke me down. He broke my husband too. Indeed, it was the first time I saw him crying. We ended up crying together. He asked for forgiveness because he was crying in front of me. That surprised me a lot, yes, because they [husbands] think they shouldn’t let us see their suffering because it brings us down. I told him I didn’t agree with him. We have to trust each other, and when I’m low I know I can look to him for support, but I can’t do that if I see that he’s not transparent with me. I told him he also needs to look out for me and, if the both of us are low then we can hug and cry together.

Although most of my informants had good relationships with their male partners, it must be stressed that these experiences are not universally applicable to all the women suffering from breast cancer or any other illness. Indeed, alongside statements of the mute, but loving, husband I found a few statements of very different import.

A common remark among my informants is that cancer makes visible who “truly loves you and who doesn’t” (Penélope). This remark refers to social networks in general. According to Noelia, a stressful event like cancer exacerbates the nature of the relationship that was taken for granted before. Simply put, if the husband was there (*estaba ahí*) before the onset of cancer, although sometimes *mudo*, there was more likelihood that, far from deteriorating, the relationship acquired a renovated strength throughout the process of the illness. But if, on the contrary, the husband was never there, the disabling, weakening and underprivileged effects of cancer provided a painful but powerful lens magnifying the absence. For example, for EllaSerYo, Marisa, Che and Amalia the experience of cancer was the revelation that their relationships were irrevocably over. Cancer was “the disaster”, “the detonator”.

Marisa, who was divorced but tried to have a cordial relationship with her “ex” for the good of her children, was extremely upset with her ex-husband’s sarcasm after she informed him about her diagnosis. He told her: “Oh! Poor you, just as you were free to enjoy yourself, this goes and happens!” To which Marisa resentfully answered back: “No, it would have been a big fuck-up if I had had to undergo this with you”. For these women, the cruelty of indifference was experienced as “the straw that broke the camel’s back” when it came to their relationships.

In sum, we should acknowledge that some behaviours conforming to normative gender ideologies are the chief causes of great stress and anxiety both for women and men. A failure to recognize it reinforces the myth that *all* men are insensitive to their wives’ needs. There are two unfortunate consequences of this. First is that men’s gendered behaviour is detrimental to them because they suffer in silence. Second, it is also detrimental to women because the responsibility for communicating and keeping the relationship afloat usually rests on them, as we will see in the next chapter when we talk about sexuality. As Arantxa told me, “health professionals could relieve women’s feelings of lack of support and men’s burden of silence by providing information and counselling to the couple *as a couple*”.

5.5. Conclusion

This chapter has focused on the nature of social networks and their role in illness legitimation and management. I hope I have demonstrated how social networks,

considered as paramount to women's well-being, can also mask unhealthy normative patterns, by combining practices that are both enabling and constraining, therapeutic and stressful.

In the first section I explored the more benign side of social networks; how they can be a safe and enabling environment for women to recover and deal with illness. In some instances the family provided security through economic help. In others, it provided material support with the practicalities of everyday living: from shopping, to cleaning the kitchen, or taking the children to school. But more importantly than anything else, it proved to be an invaluable source of emotional support which helped women navigate the uncertainties of the biomedical world. I also explored how the AECC and *la calle* were effectively, and affectingly, integrated into a sense of social support. The AECC proved to be a political space that played an important role in creating a sense of community among cancer patients, cancer survivors and their families and friends. In addition, the AECC provided free services such as psychological treatment, information about the illness and workshops. *La calle* allowed women to socialize with neighbours, friends, family, acquaintances and with the life of the city in general. The AECC and the street were embodied spaces that allowed women to clear their heads (*despejarse la cabeza*) from troublesome thoughts about cancer and gender responsibilities.

In the second section, I looked at how gender was a critical force which influenced social networks' practices of care. For example, women's daily existence as patients conflicted with the need to keep up their roles of mothers, wives and housewives. It illustrated the need to take seriously the late effects of cancer in women's lives. This chapter also illustrated how conventional gender roles also trapped women's male partners. It can be hypothesized that men's socialization impeded them from verbalizing emotions and fears. In these cases, the anxiety created by the inability to speak of one's feelings disempowered women's husbands, which then impacted negatively on women's ability to deal with their illness.

These findings argue powerfully that men should be involved in all of the steps of the cancer process. This is an important issue given that many health professionals and charities treat breast cancer as if it is solely a women's problem, rather than addressing breast cancer as a systemic disease which has impacts linked to complex social circumstances. Breast cancer affects women's partners too, and it is imperative to

acknowledge that gender rules may inhibit men from expressing their feelings. Thus, health professionals, and society in general, should create safe spaces where men are encouraged to voice their concerns and express their fears. While recognising this, it is important to engage men as co-responsible in the process of illness management. This would help men deal with their experiences of their partners' illness, and by improving the relationships they have with men, also ameliorate women's experiences.

Chapter 6

Resisting Dominant Discourses: Treatments and Embodied Knowledge

6.1. Introduction

I began this thesis by arguing that in the process of narrating, women thought reflexively about their experiences of breast cancer and, in so doing, recognition of injustice dawned on them. Narratives allowed women to recognize and put words to their concerns, aspirations, and feelings of sadness and fear, but also anger and disappointment with the health system. Many of these sentiments had been shared within their social networks, but so many others had not, or not in as much in depth as with me because of feelings of guilt, shame, or simply because they did not want to worry others. Indeed, in the last two chapters I have described several ways in which women became conscious of their situation of inequality, which was triggered, or perhaps even exacerbated, by breast cancer.

However, it was through talking about their tangible (dis)embodied sexual experiences and encounters with the biomedical establishment that women “realized rights” (Cornwall and Welbourn 2002). Realizing rights was the realization that one’s intimate, real, embodied knowledge was frowned upon or discredited, just because it was not medical knowledge. Realizing rights was about becoming aware of having been treated unjustly. For example, women realized that they did not receive adequate information about the implications of treatments on their sexual health or prospects for employment. They became conscious that their concerns had been minimized or infantilised, if not blatantly ignored. Realizing rights was also about being able to identify that there were cultural assumptions about their age or bodies that created injustices in the definition of health, as well as in access to treatments, and the quality of care they received.

In this chapter especially I will show how the body translates experiences into theory. Women's own bodies rang the alarm bell that there was something profoundly wrong with their health, and that pushed them to challenge biomedical knowledge. Thus, the body became the trustworthy vessel which shaped women's consciousness of their rights on two levels: that they have a right to the best quality of life regardless of their age, class, AC of residence, or any axis of difference; and that the biased power of biomedicine is able to define what diseases are worth researching, treating, believing or legitimating, therefore creating hierarchies between what academia or funding agencies' define as worthy of research and what women themselves experienced as a priority (Inhorn 2006).

It would be this "renewed" awareness which opened up the possibilities for social change. Social change is understood in this thesis as women's agency to challenge dominant discourses on a day-by-day basis and claim authoritative knowledge. It is also understood as women's agency to appropriate the process of participation in this thesis research as a micropolitical resistance tool through which to share their expertise and voice their desire for social and health betterment. As the vast majority of my informants stated clearly during the interviews, the intention of one of my chapters, this one, should be on creating knowledge about how the way culture defines women, and its intersection with societal ideas about women's bodies and age, has a tremendous, and often negative, influence over the types of information, advice, quality of diagnosis, dignity in treatment and care, that they receive.

Hence, the aim of this chapter is two-fold. First, I attempt to explore two aspects of breast cancer treatments which are often hidden in the dominant medical discourses, yet have significant implications for women's well being: that of the burden of living with the outcomes of armpit surgery or ALND, and the impact of treatments on women's sexual health. Second, I attempt to show how cultural assumptions about women's bodies and age shape definitions of health, and how these intersect with women's geographical location, and personal biographies, to impact not only on access to treatments but the quality of care received. Thus, this chapter endeavors to explore another level at which the violences of the social structure operate to (re)produce social inequality. I will show how social inequality is not just about problems with the failure of the ECSNS to coordinate efforts, research initiatives and cancer resources in Spain;

health professionals unconsciously (re)produce the meanings and practices of the inadequacies of the social structure as well.

In the first section of the chapter I briefly suggest how and why these lived experiences, of paramount importance for breast cancer patients' well being, remain hidden in popular discourses and overlooked in biomedical practices. Secondly, women's experiences of ALND are examined. I attempt to capture the unspeakable, immeasurable, restless intensity of the side effects of armpit surgery. I try to illustrate how women's concerns are overlooked, precisely because of the immeasurable nature of their suffering. In the final section, I explore how treatments affect women's sexual and reproductive health by presenting some accounts which diverge from the prescribed cultural norms and assumptions about gender and sexuality, particularly among older women. When given the opportunity to "generate problems", women talked about their right to reproductive health information, which includes information on sexual health and pleasure (Cornwall and Jolly 2006; Petchesky 2005; WAS 2008). They talked about sensuality or alternative ways of enjoying sexuality. These are the very issues which biomedical practitioners often assume to be secondary to cancer, or unimportant among menopausal or post-menopausal women, as reproductive health is normally defined as, and reduced to, issues of biological reproduction (Correa and Reichmann 1994; Petchesky 2003). These two examples offer additional evidence of two major challenges in of achieving the the ECSNS's goals explained in Chapter 1

6.2. Putting the Two Hidden Sufferings of ALND and Sexuality Back on the Agenda

When I ended my fieldwork in summer 2008, all my interviews revealed some issues which differed from the anthropological, sociological and feminist literature I had reviewed on breast cancer. Although I was accustomed to reading about the impact of mastectomy on women's sexuality or the debilitating effects of chemotherapy and radiotherapy, listening to women I heard that their experiences frequently revolved around two very different aspects of their treatments. Many of the women spoke in terms of unbearable pain, feelings of alienation, loss of jobs, despair, loss of libido, inability to have orgasms, sadness for losing their breasts and nipples, and even rage at the invisibility and discredit of their suffering.

Although these were oft-repeated complaints, my informants received little comfort from the health care system. In particular, health professionals appeared incapable of seriously addressing such complaints as frequently there was neither physiological evidence of a medical problem nor a clinical explanation. On top of that, women's complaints often were regarded as unimportant, secondary to cancer, or attributed to the "normal" conditions of "getting old".

This was the first time I heard about ALND and lack of sexual desire or inability to have erotic thoughts as a consequence of drugs. It surprised me I had not come across any reading on the topic. I began to learn the significance of armpit surgery and sexual concerns post-treatment by listening to women. As I became increasingly more curious about these "phenomena", I had to turn to the medical literature to learn more. This was especially striking because of the vast array of qualitative research published on breast cancer concerned with women's lived experiences. This led me squarely into the central questions of this thesis: how do Spanish women living with breast cancer define their own health priorities? Why are certain issues that seem relevant to breast cancer patients not central in the existing discourses on breast cancer? What are the mechanisms through which women's experiences are made invisible? Perhaps, British or American women (who most of the literature I have read is about) do not bear the same difficulties as Spanish women? Or it is that social scientists and women do not deliver the same message?

At first instance, I constructed three hypotheses to justify these lacunas. First, I wondered if differing surgical procedures and protocols on treat breast cancer would radically determine women's experiences of breast cancer. For example, I did not know if in America or the UK women undergo ALND as routinely as it seems to be done in Spain, or whether health professionals would favor the less aggressive selective lymph node biopsy (SLNB) instead. Second, I considered to what extent cultural differences of what Cecil Helman (1994: 185-187) regards as public pain would influence women's narratives. Helman explains that illness behaviour and public manifestation of emotions are regulated by what society and science defines as appropriate or inappropriate. In other words, I did not know to what extent it was *morally* acceptable for older British or North American women to complain about their lack of libido and ability to have orgasms, for instance, when the conversation in question was revolving *about* breast cancer. Finally, I considered whether "local biologies"(Lock 1993: xxi) would play a

role in shaping women's narratives of breast cancer. That is to say, I wondered if cultural assumptions about what is 'healthy' and public pain would, not silence, but shape Anglo-American embodied experiences of treatments in a distinctive manner.

However, the ever-increasing Anglo-American medical attention to the problems associated to ALND versus SLNB, and the intense debates that my findings on sexuality raised at conferences and discussions with informants, colleagues and friends suggested that my three hypotheses were false. Instead, the issues experienced by my informants would appear to be far from rare among breast cancer patients, in Spain as well as in Anglo-American society, despite their absence from much of the social science literature on breast cancer, let alone medical literature on the subject. Proving false my hypotheses "legitimated" even more the need for this chapter.

I have stressed so far that in much of the the medical literature focusing on women's experiences with cancer treatments, the emphasis has been mainly on the impact of mastectomy on women's body image, the side effects of chemotherapy and hair loss, and loss of identity. Quite logically, and not surprisingly, social research working on breast cancer and treatments tend to focus attention on the same problems as biomedicine, in turn reflecting its biases (Rosser 2000). This "obfuscation" can be identified with, and is reinforced by, powerful "profitable" (Zones 2000) assumptions about cancer (see Stacey 1997; Sontag 1991), femininity, and women's sexuality (Baralt 2006; Wilkinson 2001; Yadlon 1997; Lorde 1997; Spence 1988).

Whilst recognising that these are significant issues for women, there is the danger of slipping into a blindness, or rather deafness, which conditions our ability to hear those messages that do not conform to the dominant assumptions. Having said that, and as I explained in Chapter 3, I do not claim that my ability to hear voices was free from years of academic acculturation. Yet at many stages of the PhD process when I was faced with the dilemma of focusing on "mainstream" findings or exploring emerging new material which seemed important for women, as is the case of ALND and sexuality, I asked myself the Rosaldo's question "what is significant in their lives, how things matter to them" (1986: 98 in Garro and Mattingly 2000: 11).

6.3. Women's Reflections of Armpit Surgery

The significance of looking more specifically at ALND from a social scientific point of view is justified by various reasons. First of all, because of the relevance granted to it by most of my informants. The high degree of dissatisfaction with biomedicine because it failed to recognize the importance of its side-effects in their lives, the resentment with health professionals who minimized or disregarded their pain, the ambivalent feelings about the need of ALND, and the subsequent the lack of research on surgical alternatives, were oft-repeated stories during fieldwork.

Second, I learnt with horror that *axillary lymph node dissection* is done routinely to the majority of breast cancer patients in Spain. This procedure consists of the removal of the *lymph nodes* located in the armpit of the affected breast to determine whether the cancer cells have spread beyond the breast to the bloodstream (AECC 2005; AECC 2007b). Vicente et al. (2001) from the Hospital of Navarra, a world-leading hospital in the treatment of breast cancer, declared in a report that although many women will benefit from this procedure, many of them will suffer unnecessary side effects as this chapter illustrates. Despite the implications of this statement, the considerable lack of clinical research on the topic is striking.

Third, astonishingly, one third of women who undergo ALND will develop the *arm lymphedema* at some point in their lives (Turner et al. 2004). This physical cause or edema is an accumulation of lymphatic fluid. It occurs because the missing or damaged lymph vessels cannot drain the lymph properly to/from the arm. Once it appears, it can be treated and managed, but becomes irreversible.

Recent medical literature of qualitative nature has expanded our knowledge of the experience of lymphedema. It has been defined as one of the most “troublesome” and “burdensome” iatrogenic effects of breast cancer treatment. The list of effects varies but is always negative: pain, numbness, arm swelling which might develop into lymphedema if not treated on time, lack of arm mobility, and propensity to infection. The edema can have a significant impact on women's life style, hobbies, quality of life, and ability to return to paid work as we saw in the last chapter. Recent studies by Radina and Armer (2001, 2004) and Johansson et al. (2003) highlight that lymphedema may lead to psychological problems, body image problems, decreased energy, anxiety, depression, and sexual problems.

For some years now, the Spanish Federation of Breast Cancer's Associations (FECMA) has expressed its conviction that lymphedema affects women's employability. Indeed, its manifesto presented in 2005 demanded specialized lymphedema units in all hospital settings with oncology units. In addition, it called for more investigation into less aggressive procedures for node sampling, and on the links between breast cancer treatments, lymphedema and women's employability.

But the case of FECMA (2010) is more pertinent still in illustrating how certain assumptions about breast cancer and their associated problems worthy of study bear more weight than others. Although the discourses of FECMA might gain legitimacy in policy circles, like in the drafting of the ECSNS, to date they have been unable to successfully change practice at the more local level where ideologies operate: many health professionals are unaware of the distress and far reaching complications of ALND and as a consequence they do not spell out the risks; the systematic use of ALND has not been subjected to proper scrutiny despite a growing body of international opinion acknowledging that although more research is needed from the available data, first studies have indicated the efficacy or good prognosis of SLNB in case of negative node (Torres Sánchez 2006; Gallegos Hernández 2003). Finally, SLNB is practised in very few centres in Spain.

The justification for SLNB lies in the theory which suggests that the sentinel node is the first lymph node to which cancer cells will probably spread to from the primary tumour site. Because SLNB involves the removal of fewer nodes, if the biopsy determines that cancer has not spread to the sentinel node, in theory, there may not be any need to remove the remaining lymph nodes. This would avoid, or reduce at the very least, the invasive iatrogenic effects of ALND, which removes most lymph nodes in the area.

Finally, given the improvements of survival rates, research should turn now on how to improve survivors' quality of life (Velanovich 1999). In other words, the importance I give to furthering knowledge about ALND is granted because a clear majority of all breast cancer patients will be afflicted by some of the problems, if not all of them, associated with the surgery.

6.3.1. Living with Unspeakable, Restless, Terrifying Pain

Regardless of women's age or stage during the therapeutic process, four interrelated themes emerged when women spoke about their concerns with experiences of ALND. These themes were: who defines health, their right to information, questioning the routine use of ALND, and pain. These themes epitomize the main criticisms to authoritative biomedical knowledge outlined in Chapter 2.

While clinical and epidemiological studies have concentrated on the implications of lymphedema, my findings starkly make clear that not only those women who develop the edema were affected by pain and disability. To give the reader an idea of the ubiquitous nature of the pain caused by ALND, this can impede women from "simple", "small" daily activities such as combing hair, holding the hand of "my four year-old grandson during a walk", carrying a shopping bag, tying shoe laces, driving in particular changing the gearbox, lifting certain things up onto shelves, cleaning windows, playing tennis, doing sit-ups, mopping the floor, or enjoying certain sexual postures and caresses.

Pain as a consequence of ALND may be present with different intensity at different stages of the cancer treatment: right after awaking from the anesthetic of the surgery, during radiotherapy, occasionally as result of some movements, or, in the most harrowing cases, constantly. The nature of pain in the armpit was described as unbearable, inducing despair, or simply unspeakable. Frequently, women made use of metaphors to make speakable the "irrationality" of their pain in the armpit and the (absent) breast. According to Kirmayer the quality of metaphors is that they allow the listener to apprehend the "cognitive, affective and somatic" (Kirmayer 1992: 332) experiences of the illness. Indeed, the sensory regimes of metaphors on pain allow women to voice their struggle for personal and political recognition of their situation of suffering. For instance, Carlota, who underwent ALND almost a year before we had the interview, compared her "terrible pain" to the pain of having a "dagger stabbed in and ripping my flesh".

The period following breast surgery was experienced by the women as one of the most painful stages of breast cancer treatment. In my Masters fieldwork women used powerful sensory metaphors to describe their feelings of alienation, fear of an uncertain disabled future, and anguish after breast and ALND surgery. The images varied in the

following examples, but they share a sense of helplessness while suffering terrible agony.

Immobilization: When the operation finished I could not move my arms at all. I was completely immobile! I could not even close my bra myself! (Jara).

Death: At the beginning, right after the surgery, my arm was completely dead. But completely dead! Completely! It was completely stiff. (Pepita)

Uselessness: After the surgery I felt very flattened. Physically flattened. You know... I only had my mind and my eyes. It reminded me of the cockroach of Kafka's *Metamorphosis*. When you cannot move... a sensation like... like if I was useless. When you cannot do absolutely anything. It seemed impossible I could ever recover after all of that (Sara).

Back to my doctoral fieldwork, women's metaphors to put into words their feelings of pain went even further. For example, Leonor described her pain in terms of crucifixion, akin to the suffering of Jesus Christ:

After the surgery I had a bad time because I didn't have lymph nodes and I couldn't do anything. Everyday, everyday when I went to the physiotherapist I did this (walking up the wall with the fingers until she reaches the length of her arm). Every single day I did it for the nation, for the conversion of sinners, and for those who suffer from cancer. I started (walking up the wall with the fingers) counting up to three. The next day I counted up four and so on until I reached the maximum length of my arm. After that, I started other exercises such as trying to reach my ears. These made my tears run down my face, but because I had a mission to do it, I did it for love, I offered (her suffering) to someone... then I gave myself to Christ and I told him: "My Lord, you were crucified for us, and am I not going to be able to bear this for you?" I started like this up to seven or so months later. Now I can move my arms as you do.

Pain at the radiotherapy sessions, which exacerbated the pain of ANLD, was also a common complaint for many women. Radiotherapy can severely burn the skin and after some sessions it starts producing tiredness to the extent of "complete exhaustion" in

some patients. Usually, radiotherapy sessions follow chemotherapy and/or surgery to ensure that any possible cancer cells left are “burned”. This means two things: that the scars in the armpit and breast are still very tender and sore, and that women hardly have any arm mobility. Thus, it should not be surprising that raising the arm slightly becomes “an agony”, as some women put it.

Before starting the radiotherapy treatment women go to a radiotherapy testing session where the accurate points to be irradiated are marked on the body. Often these marks are dots finely tattooed in the skin so that they remain throughout the treatment allowing women to wash themselves normally. This marking session is especially important to determine the exact location of the cancer and the points to be radiated while making sure that no internal organ is damaged by the radiations. The posture adopted in this session must be exactly the same posture that women will have to bear until the last session of treatment, irrespective of whether women feel comfortable or not.

Carlota described her agony during radiotherapy sessions. She explained that she did not have the chance to complain about her uncomfortable posture because she did not know what the treatment was about. Physical pain together with the anxiety of ruining the session because she was not able to stay still created enormous distress:

When you don't know you think everything is ok. They put me in a position that was very uncomfortable for me. I was lying with my arm like this (arm raised up) and I had to make sure I kept my arm still during the treatment. You must know that the position they choose the first day is the same position until the end of the treatment. This means that if you are uncomfortable you will be uncomfortable always... What happens is that I had to put my arm like this (still and raised up) and I could not move it. I had to have that position but I couldn't. I was unable. My arm dropped over. It was awful because I couldn't move but I had to endure it. Everyday I went to the sessions I was anxious because I thought I wouldn't be able to bear that posture as my arm dropped over in pain. It was awful. My neck was in pain, my back... It was awful. It was impossible. In one of the check-ups, when the oncologists asked me how the radiotherapy sessions were I told them: 'I can't understand, why with all the advances in technology, there is nothing... there isn't a stick, a supporting point or

something. I can't understand it. It is as simple as putting something to support my arm on'. They did consider what I told them but I was told that it would have had to be done from the first day otherwise we would have to start from the beginning again. Anyway, they gave a supporting point and I could relax a bit more. Yet, depending on who put the bandages I was more or less (un)comfortable. Then, I could breathe a bit more. I suffered a lot because of the pain, not as a consequence of the radiotherapy itself but the postures.

Some women represented their pain not only as chronic, but relentless. Pain totally dominated their lives to the extent that the very fact of envisaging a future free of pain was painful. I mentioned earlier that health professionals tend to tell women that pain will disappear eventually. However, ALND related pain can remain up to ten months after the surgery as when I met Carlota, or several years after surgery as in the case of Rosario. Indeed, Rosario a breast cancer survivor, told me that the pain never disappeared completely:

My arm was in pain for some years. I didn't know what position to put my arm in. At that time I was very upset and anguished and I used to say: 'Damn it! I didn't have any ache before and is this going to be my future? It would have been preferable to end it at that moment!' It was tremendous the pain, it was tremendous. Everyday. It was distressing because it was terrible.

Later on in the conversation when we were discussing mastectomy and breast reconstruction, Rosario admitted that she did not undergo breast reconstruction surgery, because, more than anything else, she dreaded that the pain in her arm would come back with the same intensity again.

The effects of ALND can be felt in everyday actions like household chores or hobbies. Rosa Mary's account is an excellent example of how pain can affect women's everyday tasks without necessarily developing into a pathological medical condition.

I don't have lymphedema but I have a balloon in my armpit which becomes inflamed. It is the best detector of my mood, whether it is from worry, anxiety or nerves. It becomes inflamed, it hurts and is very uncomfortable. And on top of

that it is the continuous pain to which I try not to pay much attention to, but gets worse as I work. This together with the tiredness produced by chemo, radio, and *Femara*⁴⁸ make it seem that I get up in the morning already tired.

Women tried to take strategies to counteract the lack of mobility and subsequent pain if they had pushed the damaged arm too much. Carlota for example used trainers with zips or velcro fastening. She did not use anything with buttons and preferred using cotton T-shirts which were easy to remove and allowed the wound to heal better. Maribel tried to regularly change the arm with which she held her baby's hand.

Once women received information about lymphedema they were careful to prevent its onset. Small cuts or scratches in the garden, with the scissors, sewing, or playing with the cat, may end them up in the emergency room. Penélope, who was 59 and was diagnosed seven years ago, had had two serious infections in the arm a consequence of “insignificant” scratches. She always carried a small bottle of rubbing alcohol ever since the second incident. She explained:

Because you can scratch yourself with anything, I always carry a small bottle of alcohol with me. This has avoided me from getting an infection for four years now!

Although women developed strategies, frequently the arm ended up being the victim either way. Blanca said that her neck, back, and healthy shoulder blade hurt a lot since she tried to avoid overburdening her operated arm: “everything I load here (healthy arm) I overload here (neck, back and healthy arm)”.

During the interviews, however, I found a few women like Elisa or Melissa who underwent ALND years ago, but did not suffer from constant pain, yet they acknowledged that their arm got more tired and sensitive than the healthy one if they had been doing extra work. The pictures outlined above, together with the case studies presented in Chapter 4, places the study of side-effects of ALND at the top of the breast cancer research and care agenda and demands that ALND be treated as a serious issue.

⁴⁸ Femara, like Tamoxifen, is an adjuvant therapy treatment for postmenopausal women suffering from female hormone imbalance with early stage breast cancer.

6.3.2. Problematising Biomedical Knowledge: Revolt against ALND

Needless to say, the dominant model for thinking about and administering ALND is the biomedical model. In the province of cancer the main concern is to extinguish the cancer cells, and to undertake appropriate treatment and management of ALND to minimise the physiological complications such as lymphedema (Robeles 2006; Chachaj et al. 2009). Other complaints are secondary, and the “immeasurable” side effects of ALND are clearly at the bottom of the hierarchy of cancer diseases, if they ever even get the status of disease. It is crucial to highlight here that although the majority of women in my research underwent ALND, only four of them had developed arm lymphedema at the time of the interview. However, everyday actions such as fastening a bra, tying shoelaces, combing hair, lifting children, cleaning the windows, or carrying shopping bags became compromised for many of them. In the most dramatic cases, as I presented in Chapter 4, the enduring effects would comprise women’s ability to return to work.

The main reason ALND-related side effects provoke such a concern is because it is not framed in medical terms. To this day, there is not an agreed cause of what produces ALND-related pain defined by women as “terrible”, “pins”, “excruciating”, “unbearable” or which resembles “a dagger ripping the flesh”. It is worthy to draw attention to a recent study of Voogd et al. in 2003 which had to refer back to 1989 to find a *potential* explanation of why “nociceptive” or “purely sensory” (Bendelow and Williams 1996) pain is produced⁴⁹. The authors suggested that ALND pain is a consequence of a “transaction of one or more of the branches of the intercostobrachial nerve” (Vecht et al. 1989 in Voogd et al. 2003: 79). However, they concluded that most recent studies on the preservation of the intercostobrachial nerve found that it “only leads to a modest reduction of sensory deficit” (Salmon et al. 1998 and Senofsky et al. 1991 in Voogd et al. 2003: 79).

Despite the fact that there is no agreement in the biomedical literature on what causes pain and despite the fact that women reported serious discomfort, the issue of ALND remained largely unproblematised by health professionals. I found that almost no professional addressed women’s concerns seriously. Roughly speaking, the statement that pain is produced by damage of the nerve is the umbrella term used to

⁴⁹ Bendelow and Menkes (2005: 3) argue that dominant “conceptualizations of pain have focused upon sensation, with the subsequent inference that it is able to be rationally and objectively measured”.

legitimate health professionals' passivity in addressing the issue. The logic is as follows: if the damage of the intercostobrachial nerve explains the origin of pain and there is nothing one can do about it, there is not need to look for other possible etiologies nor for providing relief. The severity of the iatrogenic effects was downplayed with authoritative sentences such as: "the pain in your arm is because we have cleaned the area very well", "the pain will disappear with time" or "there is nothing we can do".

In one moving case, Mari Mar's account illustrates her and her doctor's diametrically opposing views of health. In her doctor's view cancer was over, with the subsequent inference that she was ready to leave the role of sick and resume her normal life. In contrast, Mari Mar did not yet feel cured. ALND-related disabling pain was one of the main reasons she thought she was not cured (*curada*). Her description deserves quoting at length:

One day I told my doctor he was lying because he always told me I was ok. But I don't feel cured. I feel ill and I told this to him. 'Let's see why you feel ill', he answered. 'Because I am tired. Because I have too much pain in my arm. I have pain in my back' ... also I had those problems in the lungs, in the heart... 'Therefore don't tell me I am cured because I feel very ill'. And he told me in the past tense: 'well, those are side-effects but in truth you are cured from the disease you had'. I said 'No, no, no, don't talk to me in past tense. Don't tell me I am cured because I feel very ill. I compare to myself to before I had cancer and I am a different person. A completely different person. I have too much discomfort in my arm. I am worried about when I will have to go back to work. I wonder if I will be able to do the job I did before'. And he said, 'well, you may feel ill because you have all those small things that all together make a world for you [overwhelm you]'. And I replied 'they are not a world! I am unwell so don't tell me I am cured'. And when I asked him when my arm was going to heal he answered "with the time", but it is that I see how days pass, months pass, and my arm is improving very little, very little that I don't even notice! Well, I have lesser pain than after the surgery...but still it limits me a lot. This pain I have here (breast), back and armpit... It is such a pain in the armpit... and he told me that with the time it will dwindle.

In comparison to the threat of cancer and to the troublesome lymphedema, Mari Mar's concerns about her arm problems were regarded as "small things" which did not reach the status of a medical problem. In doing so, biomedicine discredited the reality of her experience of pain and suffering. The following quotation reflects a reluctance to accept the biomedical verdict about her health. Her sarcasm and repeated insistence are permeated with a genuinely angry feeling that something was not right with her body, challenging the hierarchy of medical knowledge to define certain illnesses and symptoms. For Maribel, the definition of health should be grounded in her embodied experience, not in alienating medical dictionaries:

I asked him if he could send me to rehabilitation. He told me it was not necessary because the exercises I do at home are the same as I would have to do in rehabilitation. Well, he considered I didn't have to go to rehabilitation...it will mean I don't need it. He knows more than I do, *he is a doctor*. This [problem] is the worst for me.

The chasm between women's knowledge and biomedical knowledge was further complicated by the fact that women received almost no information about the risks associated to ALND. In spite of the dangers of lymphedema, and despite the fact that once it appears, it becomes a chronic illness because there is no known cure yet, women were not fully informed about the risks of the condition. They highlighted the need to be informed of the specific health risks related to the procedure, not only face-to-face, but also in the consent form. I was told that some of the effects of ALND were missing from what Mariam Suárez (2000) calls *programa de festejos* which refers to the consent form which includes all the written details about the explanation of the treatment procedures, related risks and benefits, as well as patients' rights.

Once again, the AECC proved pivotal to fill the gap of biomedical blindness. The AECC was referred to by my informants as the principal source of information. For example, women expressed that nobody else told them that breast cancer was more than chemotherapy, mastectomy or hair loss. Not being mentally ready to face the side-effects of ALND was described as a sudden (*inesperada*) terrifying experience which made them feel out of control. One woman, Alejandra, who was 41 and was diagnosed two years ago, described how the silence of her doctor made her think she was being a

bit of a hypochondriac. Initially she thought that she presented similar symptoms to those described in alternative sources such as the Internet but because her doctor did not attach any importance to her complaints she thought her concerns were disproportionate:

As I told you before, I would request [from health professionals] more information. Nobody explained anything about my arm. Thankfully I've read a lot but I started having doubts because the doctor didn't tell me anything about it. Later, in *la Asociación*, they told me that my arm should be treated as if it is made of glass. Because there are certain things that I did, such as hanging my bag on it, that were not advisable. I've read that even tight rings should be removed. Because the effects are irreversible.

The women who developed lymphema found information about it late, once they had developed the medical problem and had to be referred to the hospital. An off-repeated story of my informants is that they were completely “ignorant” when they entered the world of cancer in the sense that they had little knowledge of the process. They became “cancer-literate” (Pitts 2004) through experiencing the treatments. Unfortunately, as women pointed out, their expertise came late on during the experience. This means that women learned of the treatment options and side-effects once they had suffered them, which in the case of lymphema was a high price to pay.

Another common criticism women cited was that many health professionals outside the breast cancer world did not know much about the implications of ALND, pointing out that if diagnosis was delayed, it was detrimental to their arm's health. For example Gema said:

For example, I asked my oncologist: ‘my arm is swollen’ and he said: “that is a problem of circulation”. What shall I do then? How can I go to the specialist in circulation if it is a problem as a consequence of the surgery? An oncologist should have all the information.

The problem of addressing lack of information and professionals' lack of specialized knowledge could be solved only by setting up breast cancer units in all ACs. Yet, this

does not resolve the problem completely as the performance of SLNB (when appropriate) depends on whether the hospital is equipped with radiotherapy units as I explained in Chapter 1. It is worth drawing attention to the fact that alongside statements about lack of information, I found a few statements of a different nature. Gema for example sees of vital importance in informing patients of the perils of lymphedema, however, she thinks the current discourse of the AECC is becoming rather “apocalyptic”:

Then they say we can't iron. 'No, Sir - we can iron: with moderation'. I ironed because my daughter had exams and my husband couldn't do it either. It took me ages but, well, we have to do it. It is uncomfortable, but we can iron. It is a taboo we have put upon ourselves. I don't understand it. They say we can't carry weight. We can carry some, but little by little... Anyway, they should give advice to all of us from the very beginning about exercises so that the arm gets used to these activities.

The routine use of ALND was particularly criticised by women. They demanded further research on less invasive procedures of lymph sampling. This concern came up at different stages of the interviews as well as a direct answer to one of my final questions: “If you had the power to implement policies about breast cancer treatment and care, what would your recommendations for health professionals be?”

Many of my informants had heard through the Internet, health magazines, but especially through friends and friends of friends, that advances like *selective lymph node biopsy* (SLNB) were done successfully in other hospitals. The prestigious University Clinic of Navarra (North of Spain and very closed to Carolina) was often mentioned as a model, and justification, that SLNB should be implemented in *all* public hospitals with oncology units, independently of the AC, and this procedure in particular demands radiotherapy units.

The justification for SLNB lies in the theory which suggests that the sentinel node is the first lymph node to which cancer cells will probably spread to from the primary tumour site. Because SLNB involves the removal of fewer nodes, if the biopsy determines that cancer has not spread to the sentinel node, in theory, there may not be any need to remove the remaining lymph nodes. This would avoid, or reduce at the very least, the invasive iatrogenic effects of ALND, which removes most lymph nodes in the

area. Although more research is needed from the available data, first studies have indicated the efficacy or good prognosis of SLNB in case of negative node (Torres Sánchez 2006; Gallegos Hernández 2003). Sadly, only two of my informants underwent SLNB. Accidentally or not, both women were from the rich and developed AC of Catalonia.

Women believed that there was a correlation between ALND and the chronicity of their problems in their arm. ALND was blamed for great part of their suffering which did not allow them to escape the role of being sick. Penélope, who had cancer 7 years ago, illustrated this point masterly:

Penélope: I want to insist about something I think they should do. Before removing the lymph nodes they should research something else, because after the surgery the problem in the arm remains.

Ana: Were your lymph nodes affected?

Penélope: I had one out of eight with micro-metastasis (...) I don't understand why they don't do that thing with the sentinel node. I spoke to one of my sisters-in-law, who had cancer and who underwent surgery, and they didn't remove her lymph nodes. They did a test and found that they were not infected. You see, now I am more involved in the disease, before I was a novice, I didn't know anything. They told me ANLD was necessary so I did that and that's it. (...) But I've heard on TV that they are researching on other options. I don't know whether it will be done routinely now or not.

Poliana's positive experience of SLNB substantiates most of the women's suspicions about the negative effects of ALND, which in turn concurs with previous research which suggests that SLNB reduces morbidity (Ohsumi et al. 2007; Madsen et al. 2008):

They removed two lymph nodes, the sentinel node, and they did two scars so perfect that they can't even be seen. So, not even that I noticed.

Some women expressed at once rage and sadness when they found out that the removed lymph nodes "were clean". Listening to women's narratives of resistance, and drawing from Vicente et al.'s (2001) aboved-mentioned work which suggests that many women

unnecessarily suffer the consequences ALND, it seemed to me that the drastic option of ALND was parallel to the stark option of *radical mastectomy* in the 1900s “which was needlessly disfiguring because it left many women with sunken chest walls, swollen arms” (Lerner 2000: 35). Drawing from historical analyses of breast cancer treatments and customary negative attitudes towards the female body, some writers like Zones (2000), Ferguson (2000), Rosser (2000) or Spence (1988) (in Chapter 2), to name but a few, have criticized that the breast cancer body has become the perfect guinea pig of androcentric science to experiment with the vulnerable female body. Considering the implications of unnecessary removal of the lymph nodes, one of my informants, Eva, who was 56 years old at the time of the interview and had been diagnosed 6 years ago, still believed that if she had undergone SLNB she would have had more chances to keep her breast.

My prognosis was not... it was just stage I, and none of my lymph nodes were affected, that is why I think I could have kept my breast.

We also saw in the last chapter that women in paid work made a clear connection between ALND and their disability. This section also illustrated how ALND related problems are equally important areas of concern for breast cancer patients and survivors and should be addressed in future evaluation of onco-guides.

6.4. Expanding our Understandings of Breast Cancer Patients' Sexuality

I noted in Chapter 2 and at the beginning of this chapter that breast cancer has been recognized as an important social problem not only for its high incidence, but because breasts are seen to epitomize women's femininity. The underlying assumption is that to mutilate the breast is to mutilate women's beauty and sexuality. The “cult of breast cancer” research in these areas has therefore been given priority status, resulting in a plethora of recommendations, discourses, and procedures all around restoring, or normalizing, women's beauty.

One of my many motivations in researching breast cancer was to explore whether these cultural expectations were corroborated by women's real experiences. As a social

scientist I was interested in exploring the impact, if any, of breast cancer on women's sexuality from their embodied experiences. At the same time I did not want this to become another thesis on the sexuality of breast cancer patients *unless* I heard that it was of paramount importance for women themselves.

From my Masters fieldwork I knew that women were aware that in our general scientific (cultural) view there is a fixation on the sexual problems derived from breast loss. This meant that I purposely decided not to point to the issue of sexuality directly in order to avoid guiding or prompting any answer⁵⁰. So by the time I conducted to my PhD fieldwork I was a die-hard defender of the idea that if sexuality-related problems were important issues for women, these would arise naturally during the interviews. Indeed, I was pleased with my approach because although issues about breasts, breast loss, body image, and how it impacts in their sexual life (intercourse) was a very sensitive issue, I found that women felt quite comfortable discussing it when I asked what had changed in their bodies since diagnosis. For me it was crucial that women felt comfortable talking about their experiences from "inside", thus I did not want to force any answer.

However, I learnt that other invisible aspects of sexuality not related to mastectomy or body image did not come out straightforwardly. Asking the right questions required adjusting my Sonotone or hearing aids to voiceless discourses. I experienced firsthand the theories on objectivity and knowledge production explained in Chapter 3, which argue that it is impossible to ask certain questions, albeit of outstanding importance *for women*, without awareness that there is an issue. I discovered that initially I was deaf and blind to some of their issues for several reasons. First, because I lacked (dis)embodied knowledge of breast cancer. Second, I lacked knowledge of breast cancer treatments' side effects partly because I was blinded by scientific bias in breast cancer research (see Rosser 2000) where the official line was that breast cancer effects are related to body image and frequency of intercourse. Third, I took for granted my healthy, mindful body.

It was in the midst of my fieldwork when I discussed my research concerns on sexuality with Begoña Arrieta and Enriqueta Barranco, influential feminists activists and academics in Spain, that my views about asking specific questions about sexuality

⁵⁰ A similar approach to data collection was developed by Lynn and Ward (2002) in their advocacy project "Putting Breast Cancer on the Map" which aimed at making public the links between breast cancer and the environment.

started to change. Their expertise in the field of sexuality and experience of working with women for more than 30 years, vastly improved my understanding of sexuality and of older Spanish women's attitudes to sexuality. I learnt that talking about sexuality was tricky, and more if it was with older women, not necessarily because women did not want to talk about it, but because their socialization narrowly defined their sexuality in terms of "heterosexual Catholic love"⁵¹ and inhibited alternative narratives of sexuality.

In last chapter I explained how older women's socialization may have had certain degree of influence on their lack of access to higher education and consequent lack of qualifications and skills and how this affected their experiences of breast cancer later on. By the same token, the religious and cultural heritage should be taken into account as "the sexuality of older people is intimately linked to their sexuality in the past" (Nieto 1995 in Ramos Toro 2008: 30). As I already explained, older women were socialized during a time that was characterized by a strict, "quasi-paranoid" dichotomical hierarchy. In this hierarchical structure, women and homosexual occupied a lower position (Pérez-Sánchez 2007: 11). This lower position in the system made that women's sexual experiences were viewed solely within the established parameters of reproduction. The notion that sexuality could be a powerful and legitimate source of pleasure and autonomy for women was perceived almost as a heresy. Women's sexual drive and desire was defined as the uttermost tragedy of human kind: it was immoral and even pathological (Pichardo-Galán 2006: 358) According to Platero-Méndez (2009b) in *Lesboerotism and female masculinities in the Francoist Spain*, women did not have the right to seek pleasure but had the obligation of satisfying their husbands' sexual and domestic needs.

As Arrieta pointed out in our conversations, it is also essential to highlight that although the impact of this heritage varies among older women, it remains very real today. Furthermore, despite increasing important positive political changes since the latest years of the dictatorship, the traditional gender ideologies have wide-ranging influence on contemporary Spanish society, affecting not only older women's expressions and repressions of sexualities, but also younger women (Alborch 1999; Platero-Méndez 2009a), and health professionals' approaches to sexuality too.

⁵¹ See Esteban Galarza, Medina Doménech and Távora Rivero's (2005) study on Love, Health and Inequalities: Gender Identities and Women's Experiences which explore the role played by 'romantic love' in the production of gender inequalities and violence in contemporary Spain. It also examines the social and medical discourses of love in Spain during the Francoist's era.

Therefore, it is understandable that women's silences reflected their views of, and experiences with, their sexuality which were marked to some extent by negative connotations.

Arrieta and Barranco suggested that rather than addressing my attention to discourses about mastectomy or vaginal dryness as the main concerns of women, I had to be receptive to more subtle messages about what women:

are actually experiencing, what they enjoy and when they orgasm, and then draw conclusions. In other words,... to start asking them [directly] what they *do* feel sexually (Hite 1993: 55).

This approach unleashed heartbreaking accounts from women which were often disappointed and visceral, and became more and more angry as they made sense of their experiences. Women's narratives blew apart dominant assumptions about their sexuality. They decried that in many cases it is not the psychological problems of losing a breast, but treatments (e.g. radiotherapy, chemotherapy, hormone-therapy or nipplectomy), which affected their libido, their ability to have erotic thoughts, orgasms, or embodied sexual pleasure.

The question why sexuality matters in breast cancer became clear. My argument is that health professionals and researchers' approaches to women's sexuality reproduces the violences of the social structure on two levels: first, by defining sexuality in androcentric terms so that our understanding of women's sexual experiences is limited, and hence the negative impacts of treatments on their sexual pleasure goes ignored. Second, these definitions not only impact on research and practice, but deny women the right to pleasure, sensuality, and the multiple ways of having sex. In what follows I will discuss the issues that emerged from these conversations.

6.4.1.Dominant Theme: I Have a Right to Sexual and Reproductive Health

Consider the following passages:

I can guarantee that I am a sex fanatic. Fanatical yes. I loved sex. I would have had more sexual activity but my husband always worked away, so I have not

been fortunate in that sense. I was never one of those women who had headaches. Now I am enraged because I think of the past: when I wanted to, I couldn't because of the situation... the boys were also small... I would love now to take something which gives me an appetite (Rosa Mary, 47, diagnosed 2 years ago).

In my case, it has been a big change. In sex matters my husband and I get on really well, and now we have passed from having frequent sex to not feeling like it. Sometimes I think about it and I say 'damn, I have been for a month without...' 'What can I do to get aroused?' Then, it annoys me because we went from a very active sex life to absolutely nothing. It must be something that I don't know. True, I am going to ask my oncologist next time to see what he comes up with (Mari Mar, 40 years old, she was diagnosed 18 months ago).

As these fragments illustrate, the centrality of sexual pleasure in women's narrative agenda reflects the significance that they place on sexual and reproductive rights as important aspects defining their experiences and needs. A closer look at these fragments also reflects an emphasis on other important issues often absent from discussions of breast cancer. Issues of injustice in access to appropriate information, treatment, and quality of care, as well as lack of recognition of women's right to sexual health were some of the violences that surrounded biomedical definitions of what was considered 'normal' sexual problems and what was considered "abnormal". These definitions, of course, were significantly influenced by presuppositions about women's age, bodies and minds.

The dominant criticism women made was about the lack of accurate and comprehensive information relating to the iatrogenic effects of treatments on women's sexual and reproductive health. For Carmina, a 37 year-old woman who had begun menopause and who wanted to become pregnant, the lack of, or vague, information about the impact of treatments on her fertility led to considerable anxiety, sadness and rage:

They should inform more. They should explain more: what it is, what it entails... because they say: ‘you have this, we will do this...’ but they don’t say ‘these are going to be the consequences’.

As we saw with the case of ALND, the implications of the lack of information for women’s well-being are considerable. Since these symptoms were not included in the consent form, women feared that something maybe wrong with their bodies. In addition, as Enriqueta Barranco put it in one of our electronic conversations, in a culture which takes for granted that women are responsible for continuing (sexual) relationships, the sudden, but extended absence of sexual desire, contributes to the spiral of women’s suffering as they feel guilty because they cannot satisfy their husbands’ sexual needs. Arantxa put Barranco’s theory eloquently:

What is more irritating for me is, first of all, at the same that they inform you about some side-effects such as hair loss, breast reconstruction, and so on, they should also have to say: ‘Listen, Arantxa, we are going to give you these drugs, probably your libido will be affected. Don’t worry and do not feel bad with yourself’. Because women tend to blame themselves: ‘I don’t feel like...I am not able to... I don’t want my husband...’. Moreover, they should mention it in front of the partner, so both are informed and go hand in hand during the process.

The call to engage men as co-responsible in the process of illness management presented in Chapter 5 was reasserted in Arantxa’s final statement. She observed that the provision of proper information to the couple is a must so “it doesn’t become another burden for women”.⁵²

⁵² When I realized the extent of these practices, I wondered if the same happened to prostate cancer patients. It seemed unlikely that men were not informed about the effects of treatments on their sexuality. When I looked at guides and websites, I did indeed find many statements which conveyed a sense of public and medical concern for men’s sexual experiences. When a man is diagnosed with prostate cancer he is quickly informed on how prostate cancer treatments may affect his sex life and fertility. And although harmful and coitus-centric (Dowsett 2008), at the very least he will be informed about the available treatments for erectile dysfunction (see AECC 2004). More importantly, given that it is especially important for a man not to be blamed for his impotence, the Prostate Cancer Charity (2008) highlights: “If you have a partner, it is important that you involve them in any decisions you make about treatment for ED [erectile dysfunction]. The loss of sex in a relationship changes the way a couple have sex, or starting sex again after cancer treatment can also affect a relationship”.

The right to sexual health for women was, all too often, compromised by judgmental attitudes of health professionals. What was massively evident from women's narratives is that when what they knew and felt, by virtue of their (dis)embodied experiences, disagreed with social and biomedical definitions of what was a normal sexual problem, women faced being ignored, infantilised, ridiculed, or labeled as being "horny" as Arantxa put it. Worse, their knowledge was regarded as nothing but a problem of their mind. According to Kirmayer (1988: 58), these attitudes are a "manoeuvre act to maintain the rationality and coherence of the biomedical world view even while they disqualify the patient's suffering or moral agency".

Infantilisation is not a new violent mechanism of the social structure to disregard or silence women when they claim knowledge about their health or their sexuality⁵³. The following fragment reveals how the doctor underestimated Julia's capacity to understand the complex interaction of different factors affecting her lack of sexual enjoyment. An "easy" way to satisfy Julia's need for answers was telling her that she was sterile as a consequence of induced menopause.

Julia: Femara is killing us.

Ana: Did you consult your doctor?

Julia: Yes, with a young female oncologist.

Ana: What did she say?

Julia: That my estrogens are.... Well, that I am sterile. I don't know how to explain it. Something like my estrogens are dry. She left me speechless. So you can see... She told me this last time because I asked her: 'What happened? This is happening... certainly that I don't... I don't have an intimate life with my husband'. She said: 'of course' and it is when she explained to me. She left me flabbergasted and I said: 'there is an explanation!'. Because I could realize something was wrong... or it was me or it was my husband. But I know my body, that is to say, if my body does not get aroused it is because of something, isn't it? I know how my body works as you know about yours.

⁵³ There is ample evidence that infantilisation of women is pervasive in many societies. Health care settings are not excluded from these discriminatory practices as Charlotte Perkins Gilman masterly illustrated in *The Yellow Wallpaper* in 1892 (Golden 2004).

The “legitimacy” of this answer relies on the popular misconception about human sexuality that links sterility to sexual performance and sexual activity, and lately, to reproduction. Therefore, infertility⁵⁴ as a consequence of menopause is directly understood in terms of an end of sexual life⁵⁵. However, as the opening quotations stressed, it is important to highlight that many women do not experience a reduction in libido after menopause, and indeed found it liberatory because they did not have to worry anymore about pregnancy or of children being around (see Crawford 2004). This was especially true for those women who had an active and pleasurable sexual life before diagnosis.

Yet, before appropriating this argument to “pathologise” breast cancer patients’ sexuality once again (see Tiefer 2003, 2005, 2006), it is important to acknowledge a rather different understanding of menopause. According to Barranco, changes in women’s sexual behaviour around menopause can become a *cultural* form of resistance to cultural pressures on women to satisfy their husbands. That is to say, menopause becomes the perfect excuse to give up sexual relations that were never satisfactory. Thus, while many breast cancer patients may want to resume their sexual lives, many others may not. Information should be about enabling women to make choices, whether consciously or unconsciously.

Julia’s account also draws attention to the fact that nobody had informed her about the possible short and long time side-effects of treatments, or manifested any interest about her sexual health for the last 7 years. This demonstrates the critiques of the primacy of an androcentric thinking which reduces women to their reproductive capacities, and which disregard women’s right to pleasure and sexual health which are basic reproductive rights (Petchesky 2003; 2005; Correa and Reichmann 1994; see Cornwall and Jolly 2006; Cornwall and Welbourn 2002).

⁵⁴ Infertility is the inability of ‘a couple to conceive after a year of unprotected intercourse’ but infertility does not mean loss of sexual desire or loss of sexual performance.

⁵⁵ In the West, medical explanations of menopause have influenced popular and scientific understanding of the process. It seems that women start ageing when they reach menopause (Hunt 1994). Ageing, and by extension menopause, is perceived as negative, as a disease which causes physical disability, psychiatric disorders, ugliness, social disengagement, intellectual deterioration, and loss of sexual activity (Gannon 1999). This belief rests on the reproduction model which assumes that a woman’s status and identity derive primarily through her capacities to bear a child (Eckman 1998). Therefore, once that a woman stops menstruating their ovaries are “useless” as they are not longer fertile (Wester Barbre 1998: 251). Further, in considering ideas of reproduction, underlying cultural misconceptions about infertility can be seen. According to the traditional definition of fertility as being able to have sex and being sexually active, the belief is that infertility entails a loss of sexual activity.

Continuing in this vein, women's concerns about lowered libido were often minimized, attributed to the condition of getting old, or treated as secondary to cancer. It is striking that health professionals' attitudes were governed by assumptions of the "asexual menopausal vagina", and the resultant impact on the sexuality of women's husbands, not on women's. The following remarks exemplify this:

I say to myself that I enjoyed more with Tamoxifen, but with this new drug [Femara] I feel nothing at all, so I asked other women about it. And I have told to my oncologist too, and if there was anything he could do about it, and he said 'well, not much really... let your husband enjoy' (Julia).

My gynecologist told me: 'Arantxa..., by this stage of your life these are small things'... meaning 'here, the most important thing is that you are alive, so do not ask for anything else', and suggesting... 'It is your husband's problem'. Hey! I am worried about myself! That is to say, I am worried that I, as a person, am not able to fully experience my sexuality (Arantxa).

As noted earlier, cultural expectations about illness and cultural constructions of women's sexuality did not help. Many breast cancer patients had a great deal of trouble talking about sexuality. For older women this was partly because they had been socialized to regard their sexuality as basically unimportant (Béjar 2004: 69). For younger women, it was more to do with an unwritten social rule that suggests that non-breast centred women's sexual problems are trivial in comparison to the threat of cancer. Therefore, this may influence women's breast cancer experience negatively. For example, those women who behaved according to the ideal of femininity and modesty which represses women's sexuality, shied away from doctors by opting for not raising any questions about their concerns. Hence, their questions remained unanswered. On the contrary, those patients who spoke openly about their sexuality problems faced embarrassment, as frequently their complaints were diminished as being unimportant.

As I listened to women and discussed my findings with others, it became clear that these attitudes could arise because many health professionals found it difficult to respond to women's complaints either because there is not enough conclusive research

on how treatments affect women's sexual health, or because cancer health professionals have a fairly limited exposure to sexuality-related knowledge. This limitation may be exacerbated by customary androcentric cultural assumptions that reduce female sexuality to reproductive capacity.

The burden of the neurotic or "hypochondriac woman myth" (Shohat 1998), is never more present than in the breast cancer discourse, which takes for granted that breast cancer patients' complaints on sexuality are a consequence of poor psychological adjustment to breast loss. Although, this is true for many women given that the breast is a fundamental part of women's mindful body, as I will explain later in this chapter, it is not always the case as Mari Mar's words illustrated earlier on. In what follows I present alternative narratives on the impact of treatment on women's sexuality and how these are frowned upon by biomedical discourses.

A significant number of women questioned the inevitability of the link between mastectomy and sexual problems arguing that it is the treatment itself which may affect their libido and their sexual mechanical functioning. Julia, who had cancer 7 years ago and who did not have breast reconstruction but did not see herself as unfeminine, disgusting or mutilated, seriously questioned the pernicious insistence that *all* breast cancer patients' problems are body-centered.

That they are not happy being breastless, why? I really don't understand. I don't know. I don't have any... What is the relation between this (she touches her breast) and this (vagina)?

Although women presented a contrasting and rich picture of sexuality, it was Arantxa's domain of the Spanish language and sexuality issues who best articulated the complexity of how treatments may affect women's "mechanical" sexuality post treatment, regardless of health professionals' claims that women are overemotional or depressed as a result of their altered body image. Arantxa, who was retired when I met her, had worked all her adult life as a women's right activist and sexual educator. Words such as masturbation, intimacy, pleasure, desire, fantasy, arousal, clitoris, enjoyment, respect and "love your body" were an important part of her dictionary of sexual rights and empowerment education. This trajectory provided her with the opportunity to explore, enjoy and cultivate her sexuality beyond intercourse:

To start with I never needed to be penetrated to have an orgasm... moreover, for me it's negative, because my husband needs it and I never deny it to him, but I don't need it. I always worked on my sexuality, my mind, my fantasies, and it always worked terrific.

It was precisely her embodied knowledge of her sexuality that warned her that something was deeply wrong with her body:

Now it doesn't work. Effectively, this makes me question everything. I always thought that our sexuality was stimulated by our desires and fantasies, and from the feelings towards our partner, of course. I thought I controlled and directed my sexuality. That is to say, my partner could caress or stimulate wherever I asked him, in the clitoris and everywhere else, but if I didn't work my mind, if I was not in tune with what was being done to my body, it didn't work. That is why I always gave much importance to my mind. Now when my head doesn't work it worries me. I say: 'I have lost something here', then I say to myself that perhaps is not as psychological as it is said, and instead it is related to the estrogens, related to the biochemical part of our body.

Arantxa's narrative brings to the fore a poorly understood and overlooked issue in breast cancer research: the fact that women's sexual problems do have a biological component which affects their "mechanical functioning" (see Schover 1991; Bolte 2008; Martínez 2008).

The dominant model for sexuality is the biomedical model. In this model the construction of sexuality and female sexual dysfunction are framed in exclusively androcentric Cartesian dichotomical terms which focuses on the same mechanical explanations of biological processes as men's (Valls-Llobet 2003b, 2006). So when issues of sexuality are discussed by breast cancer patients and survivors, the biomedical emphasis is either on body image problems or vagina-related problems (e.g. vaginal dryness or painful intercourse). If the symptoms that women report cannot be found in the standard medical dictionary of vaginal problems, it goes from being a medical problem, to a condition of getting old or to a psychological problem. This is in turn

legitimated and reinforced by the pernicious new-age slogan which says: “Sex begins in your brain (..): free your mind, free your body” (Béjar 2004: 73).

Sadly, I found that little attention was being given to women’s embodied knowledge about the long term implications of chemotherapy, radiotherapy and antiestrogenic drugs on their sexual functioning. In Schover’s (1991) words, there is a need to pay more attention to the negative impact of treatments on the female sexual body. Moreover, more research is needed in order to try to understand the precise underlying biochemical mechanisms involved in the *physical* inability to have erotic thoughts, fantasies or feelings, get aroused, or reach an orgasm, key aspects for healthy sexual functioning as stated by the World Health Association for Sexual Health (2008: 127; see Cornwall and Jolly 2006).

6.4.2. Undefined Sex: The Significance of the Mindful Nipple

Penetrative genital sex or intercourse is but one form of enjoyable sexuality, just as the erotic breast is more than a dildo (Broom 2001) to arouse the eye of the beholder. So entrenched is our belief that the eroticism of the breast is purely visual that enjoyment or climax caused by the stimulation of the breasts and nipples, henceforth defined as “nippleism” and “breastism”, are almost completely absent from medical dictionaries of sexuality⁵⁶.

As a result, biomedical and public discourses around the negative side-effects of mastectomy tend to focus on the psychological trauma to women of not having a breast, and therefore not being sexually attractive. The “cure” for this problem is therefore breast reconstruction which is visually appealing. However, by ignoring women’s lived

⁵⁶ According to Gayle Rubin (1992: 279-280): “Modern Western societies appraise sex acts according to a hierarchical system of sexual value”. She states that the mass media fuels these assumptions and attitudes. It is worth noting that breast and nipple play is barely seen in the popular media (which institutionalizes our normal sexual behaviour). Breasts are only portrayed as sexy appendages for seducing male partners. In “mainstream porn”, breast play becomes a ritualistic part of the foreplay followed by intercourse, and often it symbolizes or represents a sort of masturbatory play (*una cubana* or *tit-wank*) where it is worth noting that “during such a process the woman does not have an orgasm. On the other hand, nippleism or breastism is seen almost exclusively in more “marginal” forms of pornography involving fetish objects, bondage, masochism or sadism. Given the value hierarchy of these different discourses of sexuality, this is why nipple or breast stimulation to the point of orgasm falls lower on the scale of sexual behaviour *and* erotic thoughts. This is the main explanation for why our language for, as well as respect for, nippleism and breastism is almost nonexistent. Indeed, this sexual enjoyment is disregarded as a symptom of “pathological” (non-normative) sexual behaviour. For example, Cristina L. H. Traina (2000) once wrote that she felt “dirty and incestuous” when “she experienced a sexual climax while suckling an infant”.

experiences, these discourses neglect the fact that for many women the trauma is in losing the sensation associated with having a mindful breast, the lived experience of which cannot be replaced by a reconstruction.

In this section I briefly use the experiences of Federico, the partner of a breast cancer patient, to illustrate the idea of the mindful breast as an example of an alternative understanding of women's sexual experiences based on nipples, which has been overlooked in breast cancer research, counseling, and surgery consent forms.

Federico defined the breasts as something that undeniably involved beauty and aesthetics for many women, but also as something "mindful" that felt pleasure, joy, arousal, or on the contrary, pain and alienation when, for example, the promise of cosmetic surgery could not restore women's breasted experience (see Hallowell 2000; Young 1990). His account spoke to the actual experience of many breast cancer patients whose breasts are an important erotic and erogenous site for sexual excitement, arousal, and even orgasm. He brings into sharp focus the idea of nippleism.

What happened to Flor is really, really, really hard. Of course breasts are important for all women but... had it been my ex-wife it would have been terrible too, but you know, for her, touching her breasts was like touching her knees. She did not feel anything. (Deep sigh) However, Flor... Flor's nipples turned her wild, really wild (*la volvían salvaje*). Her nipples turned me wild too, also her breasts.

From the very beginning of their relationship, rubbing, caressing, squeezing and sucking Flor's nipples became a surprising and thrilling new way to excite each other heavily, including for Federico, who discovered the power of nipples to increase Flor's excitement to the extent that she "turned wild". Breast and nipple play uncovered new meanings for Federico's (originally mainstream) idea of eroticism and sex(uality). Thus, breastism and nippleism became the defining characteristic of his sexual relationship with Flor.

In recounting his experience, he explained that the loss of her breasts was too heavy for Flor to bear. She had lost not only an important body part of which she was very proud, but she had also lost an important organ of pleasure which was irreplaceable in their sexual activities. For Flor and Federico, mastectomy or nipplectomy is a

euphemism embedded in the medical risk-free undamaging-sounding word ‘ectomy’ to refer to a castration of Flor’s key sexual body part. According to him, they must learn, or rather unlearn, new forms to give and share pleasure:

You asked me before if something changed...It changed overnight, abruptly. We made love in a certain way and now it is totally different.

Federico voiced disappointment with the biomedical emphasis on magical breast reconstruction more focused on aesthetics that in disclosing the impossibility of restoring the mindful or lived breast:

You have some expectations and then the harsh reality is totally different. I don’t understand why they have not developed something more natural these days... Our doctor says that now with the breast reconstruction it is possible to reconstruct the nipple and the areola, but it is nothing like the natural nipple.

Adding to disappointment and sadness, Federico’s narrative reveals how breast reconstruction alienates their breast play. After the mastectomy, one of the problems was that Flor was insensitive to the touch that once made her have an orgasm. Yet, after the reconstructive surgery, the problem was also the touch: the reconstructed breasts were scarred and unnatural to the touch, meaning that Flor not only lost her lived nipples which gave her pleasure, she also lost the direct pleasure in her hands when squeezing her own soft and malleable breasts.

Flor’s breasts had almost no fat. This means that you can feel every surgery scar because fat absorbs everything therefore you cannot feel anything. But do you know the amount of surgeries she had in her breasts? In one [breast] she only underwent surgery twice, but in the other one... we can feel all the surgeries and scars inside... That is hard.

Federico’s story calls out for the erotic mindful breast and nipple to be recognised as a sexual organ which has the ability to “feel” incommensurable physical pleasure and joy. It calls for the recognition that *for some* women breasts are an essential sex organ “quite

independent of intercourse, thought sometimes not independent of orgasm” (Young 1990: 154-155). This experience may hopefully contribute to the vast and rich body of literature on women’s sexuality. It claims for an “undefinition” of women’s sexuality which currently embodies assumptions about older women’s’ (a)sexuality as being unimportant, or secondary to cancer or to men’s desires (Berer 1999: 9); by assuming that the problem is all about having the vagina ready for penetrative purposes (Braun and Wilkinson 2001: 20-21), or by assuming that all women are anxious about their visual sexual desirability based on their breasts (Christensen 1993).

6.5. Conclusion

There are many examples of how biomedicine has contributed to post-cancer survival and the improvement of women’s quality of life, yet in some other instances biomedical responses to women’s complaints are limited. It should now be clear that cancer treatments are something more than hair loss, body image problems, or vomiting. This chapter has attempted to document other aspects of breast cancer treatments which are often overlooked in breast cancer guides, research, popular culture, and in health professionals’ practice. In particular it has focused on the “invisible” and political implications of cancer treatments in women’s “mechanical” sexual functioning and on the painful side-effects of armpit surgery.

We have seen how women’s experiences of ALND and sexuality are affected by some of the failures of the ECSNS explained in Chapter 1. But even if substantial improvements in breast cancer guides were realized, research and health professionals’ practice is likely to be shaped by Cartesian, materialistic, ageist and androcentric understandings of health women’s bodies.

Given the authority of biomedicine to chose and define which health problems are worthy of study, when women pinpoint complaints which were not recognized in the medical definition of breast cancer they were met with disbelief by those who subscribe to this hierarchy of knowledge. Ignoring, infantilising, minimising women’s complaints, or attributing their pain to everything being “in the woman’s head”, were subtle forms of structural violence which may discourage women from seeking information and treatment. This lead to a situation which produced systematic inequality in health care provision and was further aggravated on the basis on social cultural expectations about gender and age. Yet, further research is needed to determine the impact of “cultural

class” on women’s experiences in accessing healthcare. I only have incidental data to suggest that the discriminatory practices among healthcare practitioners of infantilising, ignoring and minimising women’s experiences are exacerbated among those women with lower levels of education. Also, it would be necessary to assess the impact of other axes of difference such as religion, ethnicity or disability on women’s experiences of (accessing) treatments.

If breast cancer patients’ and survivors’ health is to be improved there is clear need for women’s experiences of treatment to be taken more seriously by those carrying out research, and also for health professionals and policy makers. Berer (1999: 10) states that promoting distributive justice in health provision is about eliminating differences in health access regardless sex, class, religion, gender and also, geographical location. As Carme Valls-Llobet and Enriqueta Barranco stated in a lecture at the University Complutense of Madrid Summer School in 2007⁵⁷, equity in health entails the right to information and advice, quality of diagnosis, dignity in treatment and care, as well as follow-up cancer care and provision of resources for survivors, funding for evidence-based research on women’s specific health problems. In addition, in terms of promoting breast cancer patients’ health and sexual rights, there is an imperative to take an approach which takes into account pleasure in its multiple and subjective ways (WAS 2008; Cornwall and Jolly 2006). The right to be asexual or breastless should also be incorporated in the medical dictionary of breast cancer.

⁵⁷ Valls-Llobet and Barranco were guest lecturers of the course: ‘*Women and Health: A Gender Approach*, University Complutense of Madrid’ Summer School, Madrid, Spain, 4th-30th July 2007.

Chapter 7

Conclusion

The purpose of the thesis has been to deepen understandings of how Spanish women living with breast cancer define their own health priorities. It is meant to further our comprehension of women's health and add new dimensions to what is already known about breast cancer. To begin to address this question, I used in-depth interviews to explore women's experiences and their dissatisfactions.

This thesis aims to be contemporary and prescient in the context of a growing incidence of breast cancer in Europe and globally, characterized by the "multiplicity of knowledges" (Fosket 2000: 15) and ongoing public health policy debates, in order to help social sciences stake a claim in the study of health. As we saw in Chapter 2, research on breast cancer still remains the monopoly of biomedical knowledge, overlooking how social institutions such as medicine, and structural forces such as age, class, gender and politics, frame women's choices and strategies (Valls-Llobet 2003a, 2003b; Kasper and Ferguson 2000). This bias in social research on breast cancer is even more acute in the Spanish context, reflecting a scarcity of sociological or anthropological research in the fields of health and gender in Spain (Valiente 2002; Borrell et al. 2004a). In fact, to my knowledge, no anthropological research to date has been undertaken to explore the lives of Spanish breast cancer patients and survivors within the context of their daily existence.

In this sense, my study contributes both to the little, yet emerging, anthropological literature on health in Spain, and to the vast body of research on breast cancer, by presenting alternative ways of looking at health and illness. By listening to women I have attempted to demonstrate how it is misleading to assume that health can simply be understood in bio-physical terms. Instead, this thesis argues that there is a complex and, often, obscured background to women's experiences of breast cancer that involves the biographies of women as well as their position within the social structure.

During my research journey I realized that contemporary Spaniards, as elsewhere in the developed Western world, are accustomed to taking the implications of breast cancer in women's lives for granted. In the sense that generally, breast cancer is recognized as a life-threatening biological disease for which there are *only* specific paths of medical treatment which, fortunately in Spain, are covered by the NHS. The other public reading of breast cancer has been enthused by myths, fears and fantasies about the monstrous ways in which it mutilates women's femininity (Saywell, Beattie and Henderson 2000). Yet, less well known are other discourses which suggest that breast cancer is social inequality embodied and materialized, as these discourses have been excluded from consideration and from investigation (Wilkinson 2001; Broom 2000), which it is itself an act of structural violence. For this reason, the chief motivation for this thesis is my belief that the narratives of Spanish breast cancer patients must be heard if we, social scientist engaged with social injustices (Scheper-Hughes 1999; Wilkinson 1996), can hope to improve healthcare practice and policy.

As I mentioned at the beginning of this thesis, my work is grounded in the work of Sue Wilkinson (2001) with Celia Kitzinger (1993, 1994) on discourses of breast cancer. For almost two decades now, they have argued that women's narratives of resistance are vital for providing better insight into the dynamics and complexity of breast cancer discourses "which frame the availability of choices and treatments for cancer" (Wilkinson and Kitzinger 1993: 235).

In this thesis, narratives were used as a more egalitarian language of alliances and solidarity between researcher and informants. It aimed to take Spanish women's experiences of breast cancer into account, grounded in their embodied experiences of pain, inequality and injustice, as a legitimate form of knowledge which has been repeatedly excluded from examination and investigation (Couser 1997; Ferguson and Kasper 2000; Wilkinson 2001; Broom 2000). Yet, narratives were not used as a mere instrument to "fill the gap between ignorance and expediency" (Fairhead and Leach 1997: 35). Careful and thoughtful consideration was given to how the dynamics of power relations within the research relationship shaped the narrative encounter, as much as what I was able to hear and to represent, as well as to how women used narratives for therapeutic, empowerment or political purposes.

Whilst Hunt (2000: 101) argues that narratives "resolve long-standing social conflicts without needing to take a more radical step of defining the social structure as

oppressive”, my thesis demonstrates that women were aware of their oppression to some extent. This was made explicit, as much as implicit, by all the women throughout the interviews. This knowledge was irremediably induced by the embodied “violence” (Hegde 2009; Esteban Galarza 2004) and “pain” (hooks 1994: 59) of everyday life and by the very process of telling. I posit that the body became the trustworthy vessel which rang the alarm bell that they were being treated unjustly. This “lived” awareness would awake women’s consciousness of their rights (Cornwall and Welbourn 2002) and aspirations (Appadurai 2004) for social and health betterment. Thus, I argue that in the process of narrating, women thought reflexively about their situation in the context of roles ascribed to them by their family, society, health professionals, the health establishment and the social care system. In this sense I contend that narratives served women as a conscious revolutionary manifesto, in the most literal sense, to theorize and openly question the authority of the social structure. Yet, this theorizing may not be always articulated in hierarchical academic language and requires the “ethnographer’s textual skill and account” (Hegde 2009: 278), and modesty. Perhaps, one of the most significant contributions is that this certainty of their constraints was as liberatory, revolutionary and therapeutic as it was distressing and upsetting.

Although this thesis emerged from the work of many scholars, the notion that breast cancer is inequality embodied and materialized arose inductively out of the discussions and stories I listened to. Certainly, this theme runs throughout this thesis and has shaped the structure of the empirical chapters. This thesis brings to the fore how social inequality is tiered. It illustrates how it is not just about problems with the social structure, but also how health professionals, policy makers, social scientists, charities, social networks and women themselves all unconsciously exert structural violence by (re)producing the meanings and practices of the “inegalitarian social structure” (see Farmer 2005: 230). By unravelling the levels at which structural violence operates, I have shown how breast cancer is an example of the inverse care law which has a huge impact on women’s lives, especially those who are more vulnerable and need support most.

In Chapter 4, by focusing on the example of how breast cancer treatments affects women’s employability, I offered a new perspective on the multiples ways in which breast cancer (re)produces social inequality. I explained how older women’s life choices were influenced to certain extent by a powerful gendered socialization which

emphasised that women's role was to stay at home as wife and mother. These factors would usually prevent women from fostering a career (Santolaria, Fernández and Daponte 2004), impacting in their ability to access to benefits later on in life (e.g. unemployment benefits, pensions).

Very important for this research, and for healthcare practice and policy, are the facts that women's unforeseen life trajectories challenged gendered social prescriptions. That is to say, women do work, women in their 50s work, and that they are the cohort which is at greatest risk of developing breast cancer. Low income, widowhood, the need to care for dependents, or divorce would be some common circumstances that would force them to enter the labour market. However, women's ability to (re)integrate themselves into the labour market after suffering from breast cancer was seriously compromised by two main factors. These included the disabling effects of breast cancer treatments, in particular the effects of armpit surgery, which may alter women's strength and mobility. Also, by employment discrimination with regarded them as 'too old'. This situation was further aggravated by women's lack of employment experiences or occupational skills and place of residence, as some places or cities provide women with more resources (e.g. AECC, jobs, job-centres). Besides, the few jobs available for old and unskilled women usually required a significant amount of physical activity (e.g. housekeeping, hospitality, factory work) which many women who underwent ALND could not perform. Another problem occurred when women tried to apply for disability benefits. As most of my informants did not develop "a recognised medical problem" such as lymphedema, their complaints were discredited by health professionals, yet the social care system did not provide an alternative to alleviate their poverty.

This chapter highlighted how breast cancer affects women's (un)employability and how this increases their vulnerability to, for example, poverty. A vulnerable economic position has a clear potential to disrupt family functioning, burn out social networks, constrain social participation and leisure, which in turn increase women's chances of developing psychological and physical health problems, and social isolation.

It was evident from this chapter that when the effects of breast cancer are considered, it is imperative to take into account that women work, and for many of them work is not a choice but an obligation (Doyal 1995). Especially, as more and more women are entering the labour market and as more women are surviving breast cancer.

As I pointed out in Chapter 4, I argue that younger generations of breast cancer patients may face similar problems that older women. There are recent studies which suggest that Spanish women are still suffering the maladies of gendered expectations: women are still predominantly responsible for the household, and care for the young or elderly. Indeed, although women started participating in the labour market in the 1980s (Varela 2008: 223) and entered higher education in the last quarter of the 20th century⁵⁸ (López de la Cruz 2002), their career aspirations are put aside when they become pregnant⁵⁹ (Santolaria, Fernández and Daponte 2004), with subsequent detrimental impacts in career development, job stability, and financial security in later life. Health care professionals and policy makers need to be aware of these intersections and how they impinge on women's experiences. However, the social institutions such as the social care system and labour market whose underlying ideologies underpin women's experiences of inequality also need to be fundamentally re-organised to be more gender-sensitive and equitable.

In Chapter 5, I explored the issue of social networks which regularly emerged in women's narratives and would in themselves deserve a whole PhD thesis. This chapter contributes to the literature on social networks by exploring how they are defined by women through intertwining cultural beliefs about what practices count as support and what do not and why (Jacobson 1987).

Despite the huge body of literature on the role of social networks in health, the tendency is to focus either on their beneficial effects providing support (Eguino Villegas et al. 2007; Bloom and Kessler 1994) or in their pathogenic nature. Indeed, feminist scholarship has challenged the idea of social networks as a harmonious unit. On the contrary, they pointed out how social networks are complex relationships where conflicting values and tensions take place (Pichardo Galán 2009; Jamieson 2003; Kynaston 1996; Leonard 2001).

This thesis illustrates how social networks can combine gendered practices outlined in Chapter 2 that are concurrently enabling and constraining, stressful and therapeutic. Aside from the well-known positive role of social networks in providing social,

⁵⁸ López de la Cruz (2002) argues that in 1975 only 38% of students were women and 62% were men. These dates would only improved significantly in the last decade as for 2000/2001, 53, 03% of students in higher education were women frente a 46.97

⁵⁹ Santolaria, Fernández and Daponte (2004) argue that "motherhood impacts negatively on women's employability, whereas impacts positively to men".

emotional, financial and physical support, this thesis demonstrates how the AECC and the “street” were effectively, and affectingly, integrated into a sense of social support. The AECC and the street proved to be political “healthy” and “health-promoting” spaces where women could socialize with neighbours, friends, family and acquaintances and with the life of the city in general. They allowed women to clear their heads from troublesome thoughts about cancer and gendered responsibilities such as the role of mother and wife.

On the more negative side, this thesis highlighted how normative gendered behaviours of social networks, and of women themselves, impacted seriously on women’s ability to rest and hence on their mental well-being. For instance, women’s role of patient clashed with the need to carry on with their roles of mothers, wives and housewives. It also illustrated how men too were trapped in the tyrannies of pathogenic gender roles (Helman 1994: 162-163). An important concept here is that of the “mute husband” who was unable to speak *about his own* feelings. This was experienced not only as a source of tremendous stress among men as they suffered in silence, but their seeming aloofness also created an upsetting sense of incomprehension among women.

This thesis supports feminists’ claims of the importance of acknowledging the negative side of social networks (Hartmann 1987; Jackson 1997; Crewe & Harrison 1988) for two main reasons. First, because there is a tendency to think of breast cancer as if it is solely a women’s problem, rather than addressing breast cancer as a systemic disease which impacts emotionally on women’s social networks too. Second, because health professionals tend to ignore crucial asymmetrical gendered relationships which constrain women’s ability to accept and comply with their role as patients. Thus, while recognizing and addressing the difficulties of some members to communicate feelings, especially male partners, it is imperative to engage social networks as responsible in the process of illness management, including household chores and sexual relationships. This is, I believe, the only way to free women from their gendered roles and guilts, as well as facilitating men “to show their emotions and seek assistance in times of need or stress” (Greig 2006: 87).

In Chapter 6, I explored a different level at which structural violence operates. One of my points here was to raise fundamental questions about the aim of science, broadly defined, and the method of inquiry. I did so by exploring two aspects of breast cancer treatments which are often overlooked in research and policy making but which were

paramount for women's well-being. By focusing on the implications of treatments on women's bodies, I demonstrated how cultural assumptions about women's bodies and age shape definitions of health, and dictates what is worth researching and what is not. I also explored how these assumptions intersected with women's geographical location to determine not only access to treatments but the type and quality of care received.

In the first part of Chapter 6 I focused on the difficulties for women that arise as a result of armpit surgery or ALND. Many of the women spoke in terms of unbearable pain, feelings of alienation, unemployment, despair, and rage at the invisibility and discredit of their suffering. Although these were common complaints, women received little or no comfort from the health care system. Health professionals in particular appeared incapable of seriously addressing such complaints as frequently there was neither physiological evidence of a recognized medical problem (e.g lymphedema) nor a clinical explanation. On top of that, women's complaints were often regarded as unimportant, secondary to cancer itself, or attributed to the normal condition of "getting old". However, women resisted and challenged biomedical knowledge by making links between armpit surgery and disability, pain and morbidity. In addition, women knew that difference in health care provision among ACs and lack of breast cancer units were a serious obstacle to their accessing the best treatments available, confirming the main conclusions of the ECSNS-10 sketched out in Chapter 1.

This chapter offered an invaluable understanding of the side-effects of ALND which are difficult to capture under the current medical gaze. It contributes to the limited literature from a social perspective on armpit surgery or ALND. It buttresses FECMA's (2010) call for further evidence-based investigation on alternative and less invasive procedures.

In the second part of Chapter 6, this thesis contributes to the body of literature on breast cancer and sexuality, and to the field of sexuality broadly defined by exploring women's concerns about their sexuality. Much of the literature on breast cancer paints a picture which incorporates two compelling stereotypes on women's sexuality: that of mutilated femininity and that of the menopausal vagina. Two assumptions of these portraits are relevant here. First is the idea that sexuality problems boil down to mastectomy and its negative effect on body image. If women's sexuality is seen as synonymous with body image, and breast loss leads to poor body image and self-esteem, the link seems inevitable. Second, it seems taken for granted that women's

sexuality is reduced to intercourse (see Christensen 1983; Ganz et al. 1999; Harcourt and Frith 2008; Manos et al. 2005; Meyerowitz et al. 1999; Ghizzani 1991; Schover et al. 1995). Hence, the focus on sexuality is either on body image problems or vagina-related problems (such as inadequate lubrication), whilst scarcely addresses women's erotic and (dis)embodied sexual experiences which go beyond these concerns (Wilkinson and Kitzinger 1993, 1994).

When given the opportunity to “generate problems” (Smith 1987), that is to say without my imposing the topic, women talked about their sexual concerns and how often these were ignored, minimised, infantilised or attributed to poor psychological adjustment to mastectomy or lack of vaginal lubrication. However, explicit, tangible, and heartbreaking women's accounts which were often political, disappointed, visceral, angry and passionate blew apart prevalent myths about breast cancer patients' sexuality. They decried that in many cases it is not the psychological problems of losing a breast, but treatments (e.g. radiotherapy, chemotherapy and hormone-therapy, nipplectomy), which affected their libido, their ability to have erotic thoughts, their ability to have orgasms, and their ability to have embodied sexual pleasure. Based on the legitimacy of breast cancer patients' disembodied sexual and erotic experiences, this thesis evidenced that there is a need to “undefine” (Hite 1993: 33) oppressive androcentric medical concepts such as sexual normalcy, deviancy, function and dysfunction. This raised further questions about the importance of looking at the mindful breast and nipple as sources of incommensurable pleasure, sexual excitement, joy, and even orgasm for women, but also pain, alienation, disappointment and sadness when mastectomy removes them, when the promise of magical cosmetic surgery cannot restore their erotic experience.

More fundamentally it raised questions about women's right to sexual and reproductive health. Breast cancer patients and survivors, regardless of their age, have the right to information and advice, quality of diagnosis, dignity in treatment and care, informed by evidence-based research on women's specific sexual health problems. Of course this approach must take into account pleasure in its multiple and subjective ways (WAS 2008; Cornwall and Jolly 2006; Petchesky 2003, 2005). At the same time, it is imperative to avoid sexualizing women's experiences and to recognize women's autonomy and liberty to be asexual or breastless if they wish.

Again, taken together these findings bring to the fore the ECSNS and FECMA's (2010) demands that breast cancer units be evenly distributed across all ACs to ensure that all breast cancer patients benefit equally from the best possible diagnostic procedures, treatments and care. I think that this would improve women's experiences of ALND because more information could be shared between practitioners and women about possible side-effects and alternative procedures like for example SLNB. However, I would argue that even more joined-up breast cancer units would do little to drastically alter the way in which women's sexuality needs are addressed. This is because, as Chapter 6 illustrated, the current medical discourses fail to adequately conceptualise and understand women's sexuality. A change in health professional practice would therefore require a fundamental challenging of the underlying constructions and myths around (older) women's sexuality. A simple spatial reorganisation of current health provision would therefore be insufficient to address this.

Having said all that, I want to stress that I do not deny the biological component of cancer nor biological explanations and recommendations in this thesis. Indeed, there is no doubt that biomedicine has contributed enormously to the improvement of survival rates and quality of life of breast cancer patients and survivors. Nor is it my intention to vilify health professionals, the Spanish NHS, or the social care system. Rather, informed by women's narratives and inspired by their own aspirations, I believe that only by taking seriously the value of women's expert knowledge, women's experiences of inequality, and women's right to the best provision of health and social care available, can we move beyond limited, and unfortunately pervasive, approaches to breast cancer. Without recognition of how breast cancer can be read as an example of the inverse care law, and without questioning the everyday practices and discourses which reproduce inequality, the efforts to improve breast cancer patients and survivors' well-being will be less effective. Worse, the voices of the more vulnerable women will remain in the shadows, trapping women in the structural violences triggered by breast cancer (Couser 1997:38). It is my hope that this thesis will help to motivate, and inform others working within the field of breast cancer on how these approaches can be strengthened.

Glossary

Absolute Permanent Disability is when health problems completely hinder the undertaking of any kind of job or career. With this diagnosis, people are entitled to receive up to 100 per cent of the reference wage.

Ataxia or lack of coordination is very frequent among patients who undergo chemotherapy treatments. It is characterized by slurred speech and slowness in organizing thoughts.

Axillary Lymph Node Dissection (ALND) is the standard surgical procedure (in Spain) for the treatment all breast cancer patients. Usually it is performed at the same time as breast surgery. The main objective of this procedure is to determine if the cancer cells have spread beyond the breast to the bloodstream through the lymph nodes (metastasis) and what the next therapeutic step is (i.e radiotherapy, chemotherapy or hormonal therapy) and staging.

Axillary Lymph Nodes are situated under the arm, although **lymph nodes** are located throughout the body, being more abundant in the armpits, groin and neck.

Bilateral Prophylactic Mastectomy is the removal of both breasts for preventative reasons.

Biofeedback “is a technique that trains people to improve their health by controlling certain bodily processes that normally happen involuntarily, such as heart rate, blood pressure, muscle tension, and skin temperature. Electrodes attached to your skin measure these processes and display them on a monitor. With help from a biofeedback therapist, you can learn to change your heart rate or blood pressure, for example. At first you use the monitor to see your progress, but eventually you will be able to achieve success without the monitor or electrodes. Biofeedback is an effective therapy for many conditions, but it is primarily used to treat high blood pressure, tension headache, migraine headache, chronic pain, and urinary incontinence” (University of Maryland 2010).

Biologically Inert means that the substance does not deteriorate or cause reactions in the body.

Biopsy “used to find out whether a tumour or abnormality is cancer. Benign means it is not cancer. Malignant means that it is cancer” (National Cancer Institute 2005: 66).

Breast Cancer Screenings is “the presumptive identification of unrecognized disease or defects by means of tests, examinations, or other procedures that can be applied rapidly” (WHO 2010a).

Cancer in Situ means that cells have not spread into the surrounding breast tissue, lymph nodes, healthy organs or bloodstream. It is also called early stage or non-invasive cancer. It is curable, but if it is not treated in time it may develop into an invasive cancer.

Chemotherapy is a medical treatment based on chemical substances. It is administered to kill cancer cells. In some occasions its function is to shrink the tumour prior to surgery or to improve quality of life. Because it is non-specific, it affects all cells including healthy tissues of the body.

Curcumin is the ‘active’ ingredient of the curry spice Turmeric. Aggarwa, Kumar and Bharti (2003: 363) in reviewing research done on curcumin and its impact on health concluded: “In several systems, curcumin has been described as a potent antioxidant and anti-inflammatory agent. Evidence has also been presented to suggest that curcumin can suppress tumour initiation, promotion and metastasis. Pharmacologically, curcumin has been found to be safe”.

Duct of the Breast interconnects the lobes and conducts the milk to the nipples.

Ductal Cancer is when cancer cells develop in the ducts of the breast which interconnect the lobes and conducts the milk to the nipples.

Expander Implants are implants which are placed beneath the residual skin and muscle while deflated. Once the skin and muscle flaps have recovered from the trauma of surgery and can tolerate the stress, the implants are inflated.

Femara is a drug used for the treatment of hormonally-responsive breast cancer after surgery.

General Practitioner is the patient’s first point of contact with the National Health Service.

Hormone-Therapy is usually used to slow or stop the growth of hormone-dependent cancers such as breast cancer or prostate cancer. It consists of treatments based on hormones.

Immune System consists of “organs and cells that defend the body against infection and other diseases” (National Cancer Institute 2005: 70).

Infertility is the inability of a couple to conceive after a year of unprotected intercourse. Infertility does not mean loss of sexual desire or loss of sexual performance.

Invasive Cancer means that the malignant cells have spread into the surrounding tissue making its control and treatment more difficult. If cancer cells have entered the lymph nodes or the bloodstream it becomes a metastasis as it is impossible to stop the spread of the cells anywhere in the body. Metastatic cancer cannot be cured.

Latissimus Dorsi Flap (LD Flap) in this type of surgery a muscle from the back is brought to the front of the chest wall. The main vessels remain attached to the body to ensure proper blood supply to the flap. The LD flap provides soft tissue to allow complete coverage of an underlying implant” (BreastReconstruction.org 2010).

Lobe of the Breast is where the milk is produced.

Lobular Cancer means that cancer started in the lobes of the breast.

Lumpectomy is the removal of the lump and breast tissue around it. The aim is to leave as much healthy breast tissue as possible.

Lymph Nodes: the lymph nodes are the “cornerstone” of the lymph system. The function of lymph nodes is to complement the immune system as they produce antibodies and lymphocytes. They also act as a biological filter which cleanses the lymph before returning it to the bloodstream.

Lymphedema (arm) lymphedema is a condition where there is fluid (lymph) accumulation in the arm because the missing or damaged lymph nodes cannot drain the lymph properly to/from the arm. The risk of lymphedema increases if the patient receives radiation in the armpit as it damages the remaining lymph nodes.

Major Disability is granted when the person needs help for everyday tasks such as getting dressed, walking or eating.

Mammography refers to the screening of the breast.

Mastectomy is the removal of the entire breast (including the skin and the nipple) and the tissues that cover the chest muscles (CancerHelp UK 2009).

Metastasis is when the cancer has spread from one part of the body to another (National Cancer Institute 2005: 14).

Naturetherapy “is the system of primary health care which works with the individuals’ efforts towards the optimal expression of physiological, physical, and mental/emotional health” (British Naturopathic Association 2010).

Nipplectomy consists of the removal of the nipple and areola.

Oncologist is the doctor who deals with cancer.

Ortomolecular Diet is linked to Orthomolecular Medicine, the preservation of good health and the treatment of disease by varying the concentrations in the human body of substances that are normally present in the body through diet (ISOM 2010).

Palliative Care “is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO 2010b).

Partial Permanent Disability is granted when disability or health conditions do not impede the patient from carrying out of her/his habitual job. In this case people receive up to 33% of the reference wage.

Payas are Non-Gypsies or non-Gitanos.

Pedicled Transverse Rectus Abdominus Myocutaneous Flap (TRAM Flap) is a type of surgery in which the entire *rectus abdominus* muscle is used to carry the lower abdominal skin and fat up to the chest wall. A breast shape is then created using this tissue. In order to transfer the flap to the chest, the muscle is tunnelled under the upper abdominal skin. Since the patient’s own body tissue is utilized, the result is a very natural breast reconstruction (BreastReconstruction.org 2010).

Permanent Disability is when health hinders completely the realization of any kind of job or career. People are entitled to perceive 100 per cent of the approved costs.

Prophylactic Mastectomy is a mastectomy for preventative purposes.

Radiation Oncologist is a doctor who specializes in the treatment of cancer using radiotherapy.

Radical Mastectomy also removes the muscles of the chest wall. This operation is rarely done now (CancerHelp UK 2009).

Radiotherapy or Radiation Therapy is intended to “kill cancer cells and shrink tumours. Unlike cancer cells, most of your normal cells recover from radiation therapy. Doctors try to protect normal cells by limiting the radiation dosage and spreading

treatment out over time. When they use radiation machines, they shield as much of your body as possible while targeting the cancer. The radiation for cancer treatment comes externally, from special machines, or internally, from radioactive substances that a doctor places in your body”. (MedlinePlus 2010).

Selective Lymph Node Biopsy (SLNB) is the process whereby the sentinel lymph node is removed to check for the spread of cancer. The basis of this procedure lies in the theory which suggests that the sentinel node is the first lymph node to which cancer cells are probably to spread from the primary tumour site. Because SLNB involves the removal of fewer nodes, if the biopsy determines that cancer has not spread to the sentinel node there may be no need then to remove the remaining lymph nodes, avoiding, or reducing at least, the invasive iatrogenic effects of ALND.

Tamoxifen is an adjuvant therapy treatment that interferes with the activity of estrogen, a female hormone. Estrogen can promote the growth of some breast cancer cells. Tamoxifen works against the effects of estrogen on these cells. It is often called an antiestrogen.

Total Permanent Disability is granted when disability stops people from being able to do the basic duties of their job, but does not affect their other kinds of work. With this type of disability, one can receive up to 55 per cent of the referent wage.

Tubular Cancer is characterized by the tubular form of its cells or medullar cancer, characterized by the bigger size of its malignant cells and because it also contains white cells.

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